

Advocacy and 'Non-Instructed' Advocacy with Disabled Children and Young People with Complex Communication Needs

Jo Miriam Greenaway-Clarke

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'The thesis is submitted in partial fulfilment of the requirements for the award of the degree of Doctor of Philosophy of the University of Portsmouth'

Declaration

'Whilst registered as a candidate for the above degree, I have not been registered for any other research award. The results and conclusions embodied in this thesis are the work of the named candidate and have not been submitted for any other academic award'

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Abstract

Independent advocacy is a tool to support children and young people in decision-making, a right afforded under Article 12 of the United Nations Convention on the Rights of the Child (1989). For disabled children and young people with complex communication needs in the United Kingdom, specialist advocacy is often referred to as 'non-instructed' advocacy. To date, there is very little 'academic' research in this field, and this study seeks to address this gap. Mixed methodology is utilised to examine advocacy and 'non-instructed advocacy' through a literature review, an ethnographical study of the advocacy relationship of five children and young people and their advocates, and semi-structured interviews with eleven advocates using vignettes to replicate advocacy cases.

Taking the elements of Article 12 namely *expression, support* and *regard*, the advocacy relationship with disabled children and young people with complex communication needs is considered in the context of the wider ecosystem of the child or young person utilising Systems Theory (Bronfenbrenner, 1979). I recognise Lundy's factors (2007) of '*voice, space, audience and influence*' within Article 12 for all children and young people and add an additional factor of '*value*' in relation to disabled children and young people's participation based on my research evidence.

This research is innovative in that disabled children and young people are themselves participants in the ethnographical study. As a result of the research, I seek to reframe and challenge the term 'non-instructed' and suggest 'instruction' is on a 'continuum'. I conclude that advocates have a fourfold role of *observer, conduit, facilitator and challenger* in the realisation of the rights of children and young people, particularly those with complex communication needs. I propose a conceptual framework to support future advocacy practice with children and young people with complex communication needs.

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Glossary of Abbreviations

UNCRC ... United Nations Convention on the Rights of the Child

UNCRPD... United Nations Convention on Rights of Persons with Disabilities

BILD... British Institute of Learning Disabilities

NYAS... National Youth Advocacy Service

NDTi... National Development Team for Inclusion

UK... United Kingdom

IRO's... Independent Reviewing Officers

SEND... Special Educational Needs and Disabilities

CQC... Care Quality Commission

UNICEF... United Nations Children's Fund

IFSW... International Federation of Social Workers

DfE... Department for Education

MCA... Mental Capacity Act 2005

DoLS... Deprivation of Liberties Safeguarding

AAC... Alternative and Augmentative Communication

PECS... Picture Exchange Communication

CYP- Child or young person (This abbreviation is only used where necessary so as not to identify whether individuals are a 'child' under twelve, or 'young person' over twelve. This is necessary as the sample group within my ethnographic study was very small.)

LA... Local Authority

BAME... Black, Asian and Minority Ethnic

Introduction

Who will sing for Eddie?

As a seven-year-old in a rare 'family gathering' I realised that my cousin; my tall, dark-haired cousin who lined up toy cars in colours and size, who repeated words constantly, whose face screwed up intensely as if in agony if someone sneezed, closed a door or said his name; my cousin who was six years older than me - was 'different'. In my grandma's back room overlooking the garden, Eddie¹ became the subject of my uncle's raised voice, my aunt's tears, and my grandma's pleading that there must be other things they could do for 'it'. Eddie was outside in the garden tearing up and down with the push-along lawnmower for the eleventh time. I wanted 'it' to stop, I wanted 'it' to be okay.

I had been forbidden to go into the garden but slipped out and trotted along by the side of Eddie, trying to keep up with his long legs. Over and over again he repeated "be good, do nana's garden". As he turned, up and down, up and down, with the lawn now stripped of grass, I could not keep up with him. I liked to imagine that he slowed down for me, for in my childhood mind, that would have made my efforts to make 'it' stop, count for something.

Shortly after, I learnt that Eddie had gone away to a 'special place'. No amount of strict discipline, prayer, or consulting homeopaths could help Eddie, or rather my aunt, uncle and 'it'.

Fast forward twenty years to another family gathering. Grandma monologued about the family and then, with a change of tone, spoke softly, passionately about the one person missing - 'our Eddie'. Now an adult, I pieced together the jigsaw of a family struggling with autism in an age before autism was well-

¹ Name of cousin has been changed.

recognised, in a religious culture where conformity was everything; how they had contended with Eddy's violent outbursts and continued in vain attempts to teach him to read to prove he was 'normal'. Stories then emerged of how Eddie was moved from one institution to another having been assaulted, of losing three stone in weight, of being distressed when the only thing which would calm him would be the weekly visit of my aunt and their walk to the local chapel where she would sing to him. I know this carried on for many years, even when Eddie moved placement again many miles away, aunt found a place she could sing to Eddie.

When I heard that my aunt had died, all I could think of was –

Who will sing for Eddie?

Introduction to Researcher

The start of my journey into advocacy practice undoubtedly began in my childhood. Eddie was, without knowing, a strong influence on my early understanding of disability, in particular autism and communication and the impact on families. Years later, when training as a social worker, my final placement fell through at the last minute, and I was placed in an advocacy agency instead. At first, I was very disappointed; I had anticipated working in statutory children's services, building on my previous experience in education with children and young people. However, I soon realised the amazingness of independent advocacy as a tool for social justice, change and empowerment and thoroughly enjoyed my placement.

After qualifying as a social worker, I chose to work as a Generic and Care Act² advocate with adults. Many of my cases were, in referral, described as ‘non-instructed’ cases³. Yet I often knew that the person I was working with was able to communicate their likes or dislikes, even when they were deemed to have no capacity for decision making (under the Mental Capacity Act 2005⁴). Non-verbal communication could say so much; a slight facial change to a carer’s voice, a hand movement, changes over time to the intensity of their head-banging or the length of time they held an object of reference.⁵ Non-instructed advocacy was time-consuming and intensive, with lots of observation and conversations with carers, family members and other professionals, but I felt it was one of the most rewarding aspects of my job in getting to know individuals I worked with.

Whilst many of my ‘non-instructed’ cases were older adults I also had several young adult cases. Cases where families were struggling to cope with their adult child with challenging behaviour, where there were safeguarding concerns following a young person’s change in circumstances, cases of young people whose parents or carers were at their wits end because no plan had been made apart from an offer in a residential unit where the youngest resident was in their eighties, or tens of miles away from the activities the young person was accessing. As an advocate there was little more that I could do than hear the individual’s ‘voice’, support their rights and relay my observations of their wishes and feelings to decision-makers. Whilst sometimes the person’s voice would be acknowledged, the young adult’s voice could be drowned out by the more powerful voices of professionals, parents and social care management with

² A Care Act advocate works under the Care Act 2014. This legislation in England sets out the responsibility of Local Authorities to provide care and support services and assessments for individuals for well-being and care, including for their carers. It also covers safeguarding, information and advice about services. It aims to be person-centred.

³ Non-instructed advocacy is a term used within independent advocacy in Wales and England to refer to advocacy with people of all ages with complex communication needs. It is discussed in greater detail in this chapter and throughout this thesis.

⁴ Mental Capacity Act 2005 (England and Wales) is legislation which outlines legal framework for acting and making decisions for people (over 16) who are not able to.

⁵ Objects of reference are objects (or smells or sounds) that are used with a person to represent people, places, objects and activities.

limited resources. I knew that the young adults I worked with had their rights to advocacy recognised under legislation of the Care Act 2014 and Mental Capacity Act 2005, but I was also aware that children have less advocacy provision. When the opportunity for this doctorate was presented, I grasped the challenge. I hope that in some way, I can impact on the future provision and policy of advocacy to ensure that all children and young people, in particular whose voices are not easily understood or heard, may be listened to and acknowledged.

Eddie must be in his mid-fifties now, but I still remember Eddie as a tall, thirteen-year-old. He was part of my family; he is part of my story. My zeal for advocacy has been more than a striving for social justice and fairness, it is personal. It is about valuing and responding to the Eddies of today. Whilst my intention was to research with an open mind, I am aware that both my training and experience influenced my questioning, and that I cannot claim to be neutral about advocacy, for it is with passion I worked in the field and grasped the challenge of this research opportunity.

Before outlining an introduction to the research issue, I will introduce some key terms that appear throughout this study.

Terminology

Some of the terms and concepts that appear in the literature in relation to the themes of this research are contentious. Therefore, the following terms are explained at the outset to clarify and justify the meaning assumed throughout the thesis:

- Child and Young Person
- Voice
- Disability – definition of models of disability
- ‘Disabled’ or ‘with disabilities’?

- Advocacy 'for' or 'with'
- 'Non-Instructed' advocacy

Child and Young Person

The term 'child' and 'young person' are used throughout this research. Legislation in the UK recognises a child becomes an adult at the age of eighteen, when parental responsibility ceases. This is consistent with the United Nations Convention on the Rights of the Child [UNCRC] which also considers a *child* to be a person up to the age of eighteen. In my experience, people as young as aged ten object to the term 'child' and the term 'young person' is preferable to them. Within literature, a young person appears to be a term for an individual who is older than a young child or baby but also goes beyond the boundaries of child into adulthood. However, the age boundary is fluid. For example, The United Nations, defines a *young person* to be between the age of fifteen to twenty-four (UN, 2013) However, youth prisons (for young people) in England cater for people up to aged twenty-one and transition planning under Children and Families Act (2014) includes disabled young people up to the age of twenty-five.

For the purposes of this research I consider a young person to be age twelve to twenty-five which is broadly in line with the age a child entering secondary education to when, under the Children Act 1989⁶, a local authority ceases to have a duty of care for a young person (if in full time education). I am aware that reference to specific legislation or provision such as Mental Capacity Act 2005 is specifically age related, and therefore where necessary, the definition of the specific legislation or policy will be used in preference to my loose definition. Within the findings and discussion chapters I refer to the five children or young people of the 'live cases' without specifying whether they are 'child' or 'young

⁶ Children Act 1989 is legislation in the UK to protect and care for children up to the age of 18. It set out responsibilities and duties of parents, local authorities and agencies.

person' in terms of age. Whilst it is acknowledged that a child or young person's communication may progress and therefore age may be relevant in many areas of research, for some disabled children or young people, their communication may deteriorate as they grow due to the condition they have. I therefore considered that for this study, the age range of the child or young person was not as relevant as the relationship and communication level the child or young person had with their advocate at the time of the interaction. Notwithstanding, I am fully aware of the legislative differences applicable and make general references rather than specific references to the cases where relevant in the context of legislation.

Voice

This research focusses on advocacy as a tool to hear the 'voice' of disabled children and young people with complex communication needs, but the meaning of the term 'the child's voice' itself is contested (Murriss, 2013; Holland, Renold, Ross and Hillman, 2010). Historical and child development discourses around the ability and/or right to express opinion "children should be seen and not heard" have been challenged. Article 12 of the UNCRC states that a child has a right to have a say in decisions being made about their lives; to express themselves - have a 'voice' and convey their wishes and feelings.

For clarity, 'voice' is not limited to verbal expression but encompasses other forms of expression. Article 13.1 of the UNCRC states that:

The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

(UNCRC Article 13.1, p. 5).

'Regardless of frontiers' and 'any other media' are particularly pertinent for the voice of disabled children and young people with complex communication needs

as it recognises that the expression of ‘voice’ may be atypical and challenging to facilitate but is nonetheless a right. ‘Voice’ is not gifted through the willingness of adults, but is now a right under legislation (Lundy, 2007).

In the UK, the ‘voice of the child’ has been highlighted in policy and legislation particularly following the Laming Report (Laming, 2003) after the death of Victoria Climbié. Yet expression has to be heard and acknowledged in order to be a ‘voice’. Evidence from serious case reviews still highlight that professionals are not considering the voice of the child in their decision making with serious impacts on children’s safety and well-being (Walters, 2019; Sidebotham et al, 2016; CQC, 2016; OFSTED, 2011). Hearing a child’s voice involves taking time and willingness to build up an understanding the child or young person’s *lived experience*. This is again particularly important to recognise for disabled children and young people with complex communication needs.

I consider the term ‘voice’ to be the expression of a child or young person’s lived experience in which their wishes and feelings may conveyed.

Disability – definition and models of disability

Defining ‘disability’ is problematic with many different perspectives from different fields including legal, social and medical. In their first report on disability in 2011, the World Health Organisation [WHO] recognised that definitions of disability have shifted historically in relation to perspectives on disability and adopted a more holistic definition of disability as:

‘...the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)’ World Report on Disability 2011: p4

The United Nations Convention on Rights of Persons with Disabilities [UNCRPD] focuses on the impact of impairment on people's lives. Within the United Kingdom, the Care Act 2014 (England and Wales) and the Equalities Act 2010⁷ describe disability as a physical or mental impairment that has a 'substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities' (Section 6 of the Equality Act, 2010). This research uses the Equality Act 2010 definition.

The study of disability is not the focus of this research. Nevertheless, an understanding of the theoretical concepts and perspectives around disability enables the context of advocacy to support disabled children's voice and rights to be better comprehended. Whilst further explanation will be made where necessary within the literature and discussion chapters, in brief, within the text of this thesis, reference is made to the 'medical' model and 'social' models of disability, and perspectives and concepts around children's disability. These underpin explanations as to why and how disabled people, and in particular disabled children and young people, are viewed, valued and listened to.

The medical model is based on the perspective of impairment needing a 'cure'; there is something wrong that needs to be fixed (Shakespeare, 2006). Disability is seen as a 'tragedy' for the individual (Oliver, 1990). Whilst the medical model does not overtly deny rights, the fact that person's impairment is seen as something that needs to be fixed or addressed, implies that the person therefore has less value. This model goes some way to explain the historical treatment of disabled people and the denial of their rights (Goodley, 2004).

Since the 1970s, the 'medical' model of disability has been challenged with the emergence of the 'social model' of disability. The social model of disability turns the tables on the assumption that there is something wrong with a person, to

⁷ Equalities Act 2010 in the UK protects people from discrimination in both workplace, schools and wider society.

there being something about the society that needs to change in order for the rights to be realised, regardless of impairment (Goodley, 2004; Oliver 1990). The emergence of the social model of disability coincided with the emergence of advocacy within the UK and will be discussed further in chapter three.

The social model does not claim to deny impairment (Oliver, 2013; Shakespeare & Watson, 1997), nor debilitating medical conditions (Thomas, 2004). Nevertheless, there has been much debating and counter-debating around the social model (Mallet & Runswick-Cole, 2014; Connors & Stalker, 2007; Baker & Donnelly, 2001). Whilst disabling factors can be addressed by society, so that equality of opportunity and access is possible in many cases, Swain & French (2000) argue for the 'affirmative model' of disability that acknowledges impairment whilst also encompassing 'positive social identities' of disabled people.

Relevant to this thesis is the acknowledgement that the development of the social model of disability in the UK is largely based on the experiences of *adult* disabled people (Barnes, 2008). There is a question as to the extent to which the social model of disability can be applied to the rights of disabled children and young people (Connors & Stalker, 2007). The conceptualisation of children and 'disabled children' is further discussed in chapter one. Rights and the social models which frame the experiences of disabled children and young people with complex communication needs will also be addressed in chapter two.

'Disabled' or 'with disabilities'?

The literature concerning children and young people who are disabled, refer to "disabled young people or children", but can also use terminology "with disabilities". The term 'disabled person' is coined in social model theory (Oliver 1990, 2013) to express that the person is disabled in the context of the society. Their needs are disabling because of the inability of society to accommodate and

therefore they are “disabled”. Whereas the term a ‘person with disabilities’, implies that the disability is something to be addressed separate to that person, more akin to the medical model. Interestingly, internationally the majority of literature refers to “with disabilities” for example UN Convention on the Rights of *Persons with Disabilities*. Mallet and Runswick-Cole (2014) point out that the difference in terminology between UK and other geographical areas does not necessarily mean an opposing perspective of a social model of disability but is rather a reflection on the influences of academics within a geographical area. The UK is influenced by social modelists such as Barnes and critical disability studies academics such as Goodley and Shakespeare who coin the term ‘disabled people’ in their writings.

Literature concerning advocacy and independent advocacy within the UK, seems to be mixed. A quick google search of advocacy agency literature found some do refer to ‘Advocacy for *disabled* [young] *people*’ (Children’s Society, Action for Children, Barnardos, Council for Disabled Children) but other agencies also use ‘Advocacy for people *with* disabilities or learning disabilities’, or ‘Advocacy for people *with* dementia’ (British Institute of Learning Disabilities [BILD], National Youth Advocacy Service [NYAS], Mencap, Advocacy Matters).

I question whether there is misunderstanding of academic arguments regarding terminology. My experience is that on the ground disabled people/people with disabilities do not want to be labelled disabled first and foremost. This is affirmed by others such as Liddiard, Runswick-Cole, Goodley, Whitney, Vogelmann & Watts, (2019) and Curran & Runswick-Cole (2013) and the People First Movement. They want to be *enabled*. Initially, I chose to avoid “disability” in my title, rather focussing on the disabling issue of complex communication needs. However, during fieldwork it became clear that the use of the term ‘disabled’ may be of benefit in terms of reference for other professionals or academics and reaching specific communities, but in also defining the specifics of the use of the

term 'non-instructed advocacy' for children and young people other than very young children (pre-verbal).

For reference, I am going to refer to "disabled children or young people" as this research is concerned with the disabling barriers for children and young people with communication impairments. I consider Wickenden's argument for 'strategic essentialism' (p. 133, 2019) to be applicable. Whilst Wickenden echoes the argument of Goodley and Runswick-Cole (2016) as to issues around the use of binary term 'dis/abled' and overlooking disabled children and young people's humanness and identity as children, Wickenden also argues that a label can be useful if applied positively; akin to the affirmation social model (Swain & French, 2000). Labels also act to make visible issues pertinent to disabled children and young people that would otherwise be hidden.

The concepts of advocacy will be defined in greater depth in chapter four. The terms "advocacy with" and "advocacy for" are frequently used to describe advocacy working. I do not consider these interchangeable. Advocacy is about being a conduit for a person to express their wishes and feelings. This is in partnership *with* the individual. Advocacy *for* implies passivity on behalf of the advocated for. However, 'advocacy *for*' may be appropriate terminology when considering 'non-instructed' advocacy and therefore will be used deliberately when necessary and with qualification. The focus of this research is advocacy and 'non-instructed advocacy' for disabled children and young people with complex communication needs. It is recognised that within advocacy practice in England, Scotland and Wales, that 'non-instructed advocacy' is a specialist provision for people who are disabled by their complex communication needs, whether or not there are co-morbidities with other disabilities. A definition of disability is important but attitudes and values to disabled children and young people are key to raising of rights of children and young people with complex communication needs.

Non-instructed advocacy

Non-instructed' advocacy is the term for advocacy with clients who have been deemed as having communication impairment and/or cognitive impairment to mean that coherent or meaningful "instruction" is anticipated to be difficult to obtain by the advocate or referring professional; hence the term "non-instructed". Not being able to communicate verbally does not mean there is no 'voice' to be heard. My experience in adult advocacy is that through building communication between advocate and the person being advocated with, may determine a person is subsequently able to instruct and therefore cannot be defined as 'non-instructed'. However, a person who uses speech, may in fact have difficulties with understanding and comprehension to an extent that advocacy may therefore also be considered as 'non-instructed'. I define communication as both the receiving and giving of, understanding and meaning.

It should be noted that there is no legislation that coins the term "non-instructed" advocacy relating to health or social care. Nevertheless, Children's Commissioners in England, Scotland and Wales have recognised 'non-instructed advocacy' as a term (Longfield 2019, 2016; Baillie, 2015; Elsley, 2010):

'Non-instructed advocacy' is advocacy support which does not require children to instruct an advocate – it is used for children who cannot lead the advocacy process e.g. children with disabilities or communication needs, or babies and very young children. (Children's Commissioner for England: Advocacy for Children, June 2019, p. 11)

The concept of 'non-instructed' as a different form of advocacy to instructed advocacy, is perhaps one of the most difficult issues in terms of conceptualising what is, and is not advocacy, with impacts on advocacy provision. One of the challenges of academic research in advocacy is that much of the language of advocacy has evolved from advocacy practice, but not necessarily from theoretical groundings; the term "non-instructed advocacy" is not widely recognised in academia nor beyond advocacy services in England, Scotland or

Wales. Whilst non-instructed advocacy may be a positive provision and indeed recognised by the Children's Commissioners, there is no explicit reference to "non-instructed advocacy" within the Care Act 2014 and the Mental Capacity Act 2005. Crucially for this study, the *process* and *practice* of 'non-instructed advocacy' has not been critically analysed. My research is to focus on the processes and concepts of advocacy for disabled children and young people, specifically disabled by their communication needs.

Introduction to the research issue

If someone has heard Eddie's voice, what would he have expressed about his life, what would have been his wishes and feelings about reading, about being outside in the garden, about his Nana, about being sent away, or about his new environment? Under Article 12 United Nations Convention on the Rights of the Child (1989) [UNCRC], when decisions are being made about a child or young person, that child or young person has a right to be part of the decision-making process. A child has a right to express; have 'voice'. They also have the right to be supported to express their wishes and feelings and for that expression to be taken into account.

Advocacy is a means by which a person can be supported to express their wishes and feelings. Advocacy also helps children and young people understand their choices and rights, and to have a voice. Currently in the United Kingdom [UK], there is legislation concerning advocacy provision for children and young people under limited circumstances, but advocacy is also implied within guidelines such as for Independent Reviewing Officers⁸[IRO's] (Department for Schools, Children and Families, 2010) and Special Educational Needs and Disabilities [SEND]

⁸ An independent reviewing officer is a senior social worker whose duty is to ensure the care plans for children in care are legally compliant and are in the child's best interest.

reforms,⁹2014. Independent advocates can act to support to enable children and young people's participation in decisions in their everyday lives, as well as for 'big decisions' such as transition planning or school move.

The focus of this research is on advocacy with disabled children and young people with complex communication needs. Much of existing data evidence around children and young people's advocacy is with young people who are 'non-disabled' (Longfield, 2016; Pona and Hounsell, 2012; Brady, 2011; Knight & Oliver, 2007). There is little direct research around advocacy for *disabled* children and young people, however existing evidence is clear that provision of advocacy for disabled children and young people is not equal to their non-disabled peers (Longfield, 2019; Brady, 2011; Franklin & Knight, 2011).

There are particular issues with access and specialist advocacy provision for disabled children and young people (Franklin & Knight, 2011; Mitchell, 2007), especially those with complex communication needs. When a person cannot instruct an advocate directly, by virtue of their communication needs, and/or their ability to understand and process information, advocacy is sometimes known as 'Non-Instructed Advocacy' and there are several methods for carrying out 'non-instructed advocacy' (Advocacy QPM, 2014; Voice, n.d). Neither the *concept* of "non-instructed" advocacy nor the *practice* of advocacy with disabled children and young people has been researched in detail (Brady, 2011; Franklin and Knight, 2011; McGrath, 2010).

This research addresses the gap in research as to the evidence, practice and concepts of advocacy and 'non-instructed advocacy for disabled children and young people. The relevance of this research will now be outlined.

⁹ Code of Practice which gives guidance on the special educational needs and disability (SEND) system for children and young people aged 0 to 25, enacted September 2014

Relevance of the research

The number of children aged five to sixteen identified with complex needs (severe, profound and multiple) has doubled since 2004 (Pinney, 2017). Advancement in health has improved survival rates of very premature babies and the increasing life expectancy of children with life limiting illnesses. These children and young people are more likely to have complex communication needs and therefore more likely to be considered as “non-instructed” cases. Pinney (2017) notes that little research has been undertaken regarding the resource and support needs of disabled children and families, but the implications of the evidence is concerning due to the increased numbers of children yet decreasing budgets of local authorities. Advocacy and ‘non-instructed’ advocacy for children and young people with complex communication needs is therefore potentially *more* necessary to ensure that their rights are upheld under such pressures. Whilst parents are rightly strong advocates for their children, and indeed professionals advocate, this thesis concerns the right to *independent advocacy* to voice, challenge and have rights upheld for children and young people with complex communication needs whose voices are not easily heard (Longfield, 2019; Underwood et al, 2015; Cossar et al, 2013; Wickenden, 2011).

Concerns were raised about the rights of disabled children and young people being addressed, including rights to participation and support through advocacy provision to the United Nation Convention on the Rights of People with Disabilities [UNCRPD] (Longfield, 2017). Longfield’s latest report on advocacy in England highlights once again the continuing lack of consistent, skilled and timely advocacy support for disabled children and young people, including children and young people accessing ‘non-instructed’ advocacy. The interim report of the Care Quality Commission [CQC] concerning restraint, seclusion and segregation (CQC, 2019), also mentions advocacy in relation to supporting the voice of children and

young people with mental health and learning disabilities and/or autism, subjected to restraint in residential assessment units.

Whilst there is a growing recognition of advocacy as a tool for supporting the voices of children and young people, including those with complex communication needs, there is little academic research into the role. Nevertheless, there is growing evidence and research around ‘agency’ and ‘voice’ of disabled children and young people in participation (Brady & Franklin, 2019; Liddiard et al, 2019; Greathead, Yates, Hill, Kenny, Croyde & Pellicano, 2016; McNeily, McDonald & Kelly, 2015; Underwood, Chan, Koller and Valeo, 2015; Georgeson, Porter, Daniels, and Feiler, 2014; Wickenden, 2011). This research hopes to span the gap between advocacy practice and academic research.

Aims and research questions

The focus of this research is on advocacy and what is often referred to as ‘non-instructed’ advocacy, with disabled children and young people with complex communication needs. Whilst advocacy is a recognised tool for supporting the rights of children and young people, the practice of advocacy and the impact upon the rights of disabled children and young people with complex communication needs has not been researched in detail. The research seeks to address this gap.

The aims of this research are:

- ◆ To gain a deeper understanding of the use of advocacy as a mechanism for ensuring that the views of disabled children and young people are central to decision-making about their lives.

- ◆ To understand and examine the evidence for, and practice of, what is currently termed “non-instructed” advocacy with disabled children and young people.
- ◆ To develop a conceptual framework of advocacy in order to advance future effective advocacy practice with disabled children and young people with complex communication needs.

In order to achieve the aims of this research, the following research questions will be considered:

- What is the evidence of advocacy practice in this country for disabled children and young people with complex communication needs?
- What does ‘non-instructed’ advocacy mean? Is it an appropriate term for advocacy with disabled children and young people with complex communication needs?
- Does advocacy enable ‘voice’ for disabled children and young people with complex communication needs? If so, how?
- What factors impact upon independent advocacy practice with disabled children and young people with complex communication needs? How might this inform and shape future policy and practice?

Methodology, Scope and Limitations

This research incorporates the practice of advocacy with theoretical frameworks and concepts of child and rights, disability and communication, particularly in relation to the rights of children and young people in participating in decision-making, a right afforded by Article 12 of the UNCRC. Advocacy is a tool to support a child or young person's expression. To date, there is very little 'academic' research in advocacy as a tool for participation. In order to explore advocacy for disabled children and young people and answer the research questions, three methods were used to collect data.

A literature search of documents related directly to advocacy, children and young people, and disability within the UK was conducted. This was to understand the scope, provision and access to advocacy currently documented, and to discover any previous research regarding advocacy that included direct research with disabled children and young people with complex communication needs. The terminology of non-instructed advocacy was also important to explore within existing literary evidence.

An observational ethnography of five children and young people and their advocates was carried out to explore the micro-level of the advocacy relationship, the context and practice of advocacy with children and young people with complex communication needs. The final data set consisted of the records of thirteen visits in eight settings, with in-depth interviews with four advocates after and/or during the duration of period of advocacy. Reflections in addition to notes on a specifically designed observation framework, and three detailed observations of non-verbal communication interactions, were also gathered.

To support the evidence of advocacy practice in the UK, eleven advocates were also interviewed. The semi-structured interviews included the use of vignettes to explore aspects of advocacy working with advocates with experience of working with disabled children and young people in a 'non-instructed' capacity.

Whilst this research has focused on disabled children and young people with complex communication needs, I believe that many of the findings could apply to all children and young people, particularly around 'non-verbal' communication and access to advocacy. The questioning of the term 'non-instructed' may also have implications for adult advocacy. Indeed, my 'cube of instruction', which encourages the advocate to look at the means, intention and context of communication on a continuum, could be applied to all ages.

This research has been limited by the small number of children and young people directly involved in this research. Yet ethnographic study of the advocacy relationship with children and young people with complex communication needs has not been attempted before. The triangulation with literature evidence, and interviews with advocates endeavours to mitigate some of the limitations of the small number of participants, although it is recognised the range of complex communication needs of the participants cannot claim to be representative of all children and young people with complex communication needs.

From the evidence of the interviews, the experiences, training and knowledge of advocates varied tremendously. Whilst this could be indicative of advocacy across the country, and indeed the recent findings and concerns of the Children's Commissioner for England report on advocacy (Longfield, 2019) supports this, I am reluctant to draw too many conclusions, particularly as vignettes are not 'real-life' situations. Nevertheless, this research could be used to support advocacy agencies develop advocacy practice, especially for disabled children and young people with complex communication needs.

Overview of Thesis Structure

In the first three chapters, the themes of the research are deliberated. These themes were identified as the underlying concepts that needed to be explored in order to achieve the aims and answer the research questions. Advocacy with disabled children and young people with complex communication needs is the main focus of this research, but it is pertinent to first discuss the concepts of childhood and rights, as advocacy is a tool to enact those rights. Exploring disability and disabled children as communicators and participants helps identify the opportunities and challenges for advocacy practice with children and young people with complex communication needs. It is recognised that the focus of this thesis is the practice of advocacy in the UK, therefore the majority of literature relates to education, health and social care theory, policy and practice pertinent to the experiences of children and young people in the UK.

Chapter One: Concepts of childhood and rights

Chapter one explores what is meant by 'childhood' and 'rights'. The United Nations Convention of the Rights of the Child, and in particular, Article 12 of the UNCRC as a key to the justification of advocacy for children and young people is discussed.

Chapter Two: Disabled children and young people as communicators and participants

Chapter two bridges the concepts of rights of children and young people within chapter one, with the enactment of rights through the tool of advocacy in chapter three. This chapter addresses disabled children and young people with complex communication needs as communicators. The realisation of the rights of participation by disabled children and young

people in decision-making is discussed, and a conceptual framework for examining the research is introduced.

Chapter Three: Advocacy as a tool for participation

Chapter three explores the concepts, history, scope, purpose of advocacy with focus on the legislation surrounding advocacy and advocacy practice within the UK. Consideration is also given to advocacy in social work and advocacy theory and 'systems theory' as a theoretical framework for this research is introduced.

Chapter Four: Methodology

This chapter is a justification for the methodology and approach adopted. It is a discourse on the research journey; from planning and adapting and carrying out to analysis of data.

Chapters five to nine explore the findings of the research and discuss and consider the 'voice' of disabled children and young people supported through independent advocacy.

Chapter Five: Advocacy and 'non-instructed' advocacy with disabled children and young people with complex communication needs in the United Kingdom; a review of literature

This chapter explores the evidence of advocacy for disabled children and young people, particularly with complex communication needs, in the UK. From analysis of the documentation, several themes emerge regarding current advocacy provision in the UK which are discussed.

Chapter six, seven and eight discuss the findings of the research, in particular the ethnographic study and the interviews with advocates, using the elements of Article 12 of 'Expression, Support and Regard' in three discrete chapters. These elements of participation for children and young people with

complex communication needs within the study are considered in the context of their ecosystem, using systems theory as a theoretical framework outlined in chapter three and the conceptual framework outlined in chapter two.

Chapter Six: Expression; children and young people as communicators

Chapter Seven: Support for the ‘voice’ of children and young people with complex communication needs through advocacy

Chapter Eight: Regard; attending to children and young people’s ‘voice’ through advocacy

Chapter Nine: Realisation of Rights; towards a framework of practice for advocates

The findings and discussions from the previous three chapters are brought together to consider how the rights of children and young people are actuated through advocacy. I conclude with a summary of the answers to the original research questions and draw together all the elements and factors into a new conceptual framework of advocacy.

Chapter One:

Concepts of childhood and of rights

This research concerns children and young people's rights, in particular their rights of participation in decision-making. In order to identify how advocacy can support a child or young person's participation, the underlying concepts of what are meant by 'child and childhood', 'rights' and 'rights-of-children-and-young people-to-participate-in-decision-making' need to first be explored. In this chapter, the historical, legal and social contexts of child rights are considered, with particular attention to the UNCRC Article 12 and the application of children's rights within the UK through legislation. Particular reference is made to the rights of disabled children and young people. This is not to separate the rights of disabled children and young people from those of their non-disabled peers, but to highlight the issues of the realisation of their rights particularly around participation by virtue of their complex communication needs.

This chapter is divided up as follows:

- 1.1 Concepts of Childhood
- 1.2 Rights and Child Rights
- 1.3 Child Rights under United Nations Conventions
- 1.4 Article 12 UNCRC
- 1.5 UK legislation and Guidelines on Children's Rights
- 1.6 Children's Experience of Rights
- 1.7 Rights of Disabled Children and Young People

1.1 Concepts of Childhood

Whilst this thesis is concerned primarily with advocacy practice within the UK, it is important to acknowledge that both “child” and “rights” are concepts which are globally recognised, but understood in the context of the cultural, political and social contexts of the child (Singal & Muthukrishna, 2014). Meadows (2013) highlights that the historical influences of the state and the church as well as other factors such as poverty and family practices, have helped define what is understood to be the transition between child and adult *within the UK*. Whilst the UNCRC does appear to define a child as being under the age of 18, it also adds the proviso- unless "*under the law applicable to the child, majority is attained earlier*" (Article 1 UNCRC 1989, p. 4). It cannot therefore be assumed that there is a universal definition of child or childhood or a consensus as to when a child becomes an adult. Nevertheless, it appears to be generally accepted that infancy is distinct from adulthood, and that there are physiological and psychological changes that occur (United Nations Children's Fund [UNICEF], 2005).

The progression of development from birth to adulthood is often defined in stages, but the movement between the stages and how this movement is enabled, is argued from many different perspectives. In psychology, cognitive developmental theorists such as Piaget (1953, cited Wood, 2007) believed that children construct knowledge and need to pass through the stages of development to reach maturity. Vygotsky (1978, cited Wood, 2007) considers the importance of people around the child providing scaffolding for learning and development between stages. Neo-Cognitive Theorists (Lansdown, 2005) however see children as active participants and acknowledged that children and adults have different capacities in different areas at different times. Bronfenbrenner's systems theory (1979) does not put development into stages but considers childhood within the context of their individual ecosystem. Both

Neo-Cognitive and System theorists recognised the importance of the environment and the context of the child in their development.

Much more could be said about the various psychological and sociological perspectives of child development. Precaution must be taken to universalize concepts, as theories are typically based on Western views of childhood (Boylan & Darylmp, 2009) and focussed on the development of the 'typical' child. Important to this research is the shift in sociological perspectives on childhood, from children being seen as passive recipients of socialisation (James & Prout, 1997; Qvortrup, 1994), to viewing children as active beings with 'social agency' in their own development.

Children as 'agentic beings' - able to exercise 'social agency', has implications for children and young people enacting their rights of participation (Clark and Richards, 2017) a key concept in advocacy practice and the rights of a child outlined in the United Nations Convention on the Rights of Children (UNCRC). Children are contributors in their own social worlds, yet also are influenced by the contexts of their lives (Edmonds, 2019). This may be through for example their geographical location (Tisdall & Punch, 2012), related to their social or health status (Brady, Lowe and Lauritzen, 2015) or disability status (Wickenden, 2019). The development as agentic beings can be both reduced and enhanced by the situation a child is in, but also the power interaction of the people around them (Holland et al, 2019). Sirkko, Kyrönlampi and Puroila (2019) for example, demonstrates that classroom practice can reduce agency and therefore agentic participation of children within the classroom.

Disabled children as 'social agents' may be viewed differently (Browne & Millar, 2016; Tisdall, 2012) and there is much evidence that disabled children are socially marginalised (Mepham, 2010) and lack the agentic status of their 'non-disabled' peers (Wyness, 2006). This will be discussed further in Chapter 2.

1.2 Rights and Child Rights

The concept of rights and the defence of rights has a long history, long before the Declaration of Human Rights of 1948. Historically, justice has been based on the protection, or reparation for the violation of rights. Rights were formally recognised for some as evidenced by the Cyrus Cylinder (539BC) and Magna Carta (1215). However, it is clear rights were not universally recognised as being rights for all; a prime example is people in slavery.

After the Second World War, the newly formed United Nations drew up the Universal Declaration of Human Rights (1948). There are thirty rights defined by the Universal Declaration of Human Rights. These rights apply to *all* humans regardless of age and ethnicity, disability status or country of origin. However, it is questionable whether the universal *declaration* of rights was based on universal *value* of rights. The International Federation of Social Workers [IFSW] and United Nations [UN] note particularly the violations of the human rights of women and refugees (UN, 2016). Whilst the UN's aims were noble, the ratification of those rights into laws within the countries signing up to the declaration was not enforceable.

Children's rights in the context of human rights needs to be considered; how and why do children's rights need to be defined? O'Brien and O'Brien (2000) argue that violations of children's rights are also violations of human rights. Crucial to this question is the attitude and weight of the *value* of the rights of a child given by adults (Walker, 2011) and the notion of autonomy of the individual child to the 'sameness' of rights. Three broad perspectives on the rights of children were identified by Lindsay in 1992 (cited Boylan and Darlymple, 2009). Firstly, the *protectionists* who see children as subjects to be protected. Secondly, the *liberationists*, who see children as fully equal to adults, self-determining and autonomous. A third middle-of-the-road perspective is that of the *pragmatists*

who see that children's rights need to be balanced with adults acting in their best interests. Boylan and Darlymple (2009) conclude that there is no straightforward concept of children's rights. Evangeline Jebb and her *Charter for Children* is considered a turning point in the recognition of the rights of children (Watson, 2009) and was highly influential in the adoption by the League of Nations in 1924 of the Geneva Declaration of the Rights of the Child.

1.3 Child Rights under UN Conventions

Following the post-war Declaration of Human Rights, Poland was instrumental in pushing forward for a separate Declaration on the Rights of the Child, and this was achieved in 1959 although not ratified by many countries immediately. The protectionist and paternalistic nature of the declaration began to be challenged in the 1970s, particularly after the International Year of the Child in 1979 (Boylan & Darlymple, 2009), leading to the United Nations Convention on the Rights of the Child in 1989. The UNCRC was ratified by the UK in 1991.

Whilst much of the UNCRC declaration continues to be concerned with the *protection* of children from harm of exploitation, it reads very differently to the earlier Geneva convention. There is clear shift to the recognition of the child as a *separate person*, for example, Article 7 of the UNCRC in the right to citizenship. Furthermore, the recognition of the right of a child to have their voice (Article 12) extends to children's voices contributing to policy making (McCafferty, 2017; UNICEF, 2015).

The UNCRC sought to consolidate the rights of children based on the *value* placed on rights within the committee countries, or at least the ideal *assumed rights*. In order to *assure* those rights, ratification of those rights within each country, and adoption into legislation has to take place. Despite ratification in the majority of

countries, the manifestation of the Convention through the adoption into specific legislation varies from country to country. For example, prosecution and punishment for the violation of rights including rape of children varies in different countries. So, whilst the right to protection is offered on one hand by the convention, children are subject to the rule of the land on which they live for that protection to be manifested. Whilst it must be considered that the UN Convention was influenced heavily by Western European thinking (Boylan & Dalrymple, 2009) for some issues, UNICEF and other human rights organisations are highly critical of countries justification on grounds of culture regarding child brides, for example, as there are health implications of early childbirth, and questionable practices akin to slavery of young girls once they are married (International Center for Research on Women, 2016) in violation of Human Rights Declarations.

Walker (2011) views the rights of the child as being both *fact* and *process*. Rights are both assured and factual in that they are stated, but also are enacted and realised in the process of living; the process is ongoing. For example, a child has an assured and factual right to education, but is enacted throughout their childhood, through their attendance at school and as they learn.

UNICEF identifies four core principles within the UNCRC. Non-discrimination, best interests, rights to life, survival and development, and respect for the view of the child. The articles of the UNCRC fall broadly into three focus areas; provision, protection and participation (Jones, 2011). Whilst it is important to consider the convention in its entirety (Lundy, 2012), *participation* and “respect for their view of” children and young people with complex communication needs is crucial to this thesis. Facilitating a child or young person to contribute and participate in decisions about their lives is particularly challenging for advocacy practice.

1.4 Article 12 UNCRC

Focus will now turn towards looking particularly at Article 12, because this is frequently cited in the justification for advocacy with children and young people as a tool to support the right of *participation*. Article 12 states that:

1. Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law. (United Nations Convention on the Rights of the Child, 1989, p. 5).

Three elements can be identified. Firstly, the assurance of the right of free *expression*, secondly; an assurance of provision of *support* to express, thirdly the assurance of *regard* of the views expressed. Participation through enabling voice to be heard, also recognises children and young people as social agents by regarding their voice. Lundy (2007) identifies four factors in the realisation of Article 12. Lundy's model was first developed in the context of children's participation in education recognising that 'voice' in itself was not enough to facilitate participation. The four factors are: *Space*: the opportunity to express their views. *Voice*: facilitating of expression of their views. *Audience*: their view must be listened to and finally, *Influence*: the appropriate acting upon the child or young person's views. Lundy's model has been applied in many different fields such as to child welfare practice (Kennan, Brady & Forkan, 2018), Child protection (McCafferty, 2017), and healthcare (Donnelly and Kilkelly, 2011) and is therefore highly appropriate in considering the participation of children and young people in decision-making through advocacy. We shall return to Lundy's four factors in due course.

One of challenges of the UN declaration is in its openness to breadth of interpretation by both government agencies and individuals such as social workers (Krappmann, 2010). This is particularly around the influence of the child or young person's view, and whether a child's right to expression and regard could be interpreted as being conditional; based on the *maturity and capacity*:

“the views of the child being given due weight in accordance with the age and maturity of the child”. (UNCRC 1989 p.5).

This begs the question as to whether a child's capacity needs to be proven before due weight can be given to that opinion, in other words, is this an *earned* right? Is the right *acquired* through increasing age and understanding, or is it *assured* despite age and maturity based on the assumption that every child has a right to expression, and it is for others to understand that expression in whichever form it takes? These questions will be considered in due course and is a particularly pertinent to disabled children and young people.

Children's rights are heavily dependent on the recognition of the society in which the child lives for rights to be fully realized. This applies to all articles of the convention concerning protection, and provision, as well as participation. The Children's Commissioner report (2017) on provision for disabled children within the UK highlights the issues and failings of the UK government in addressing the rights of the disabled child, particularly in relation to participation. Assumptions are not only made regarding their chronological age, but also about their understanding and capacity because of their “disability”. The acquisition of the right to participation and the degree to which a child or young person acquires those rights, could be subject to the willingness of people around them to support their acquisition of rights. Article 12 part two, clearly states the obligation to support the child and young person in expressing and being heard, and/or being represented in order that their participation is expressed. The acquisition of the knowledge of rights and the realisation of their right in participation becomes the result of the society around them imparting that right.

1.5 UK legislation and guidelines on children's rights

The legislation and guidelines for children and adolescents in the UK in terms of both their given rights and responsibilities will now be considered as these have consequences for the interpretation of Article 12 within the UK, and significance for advocacy practice.

When we consider the 'capacity and maturity' of children to be involved in decisions about their lives, it is useful to reflect on the balance of responsibility that is placed on children and young people in regard to criminality. The age at which a child can be said to be capable of making decisions and understand the consequences of their actions, and therefore be criminally responsible, varies from country to country. As yet, international law has not addressed the minimum age of prosecution, but it should be noted that criminal tribunals regarding atrocities in Rwanda and former Yugoslavia have not involved prosecutions for people under the age of 18 at the time of offences. Rule 4 of the Beijing rules and the UN committee (2007) caution the minimum age of criminal responsibility should be above twelve years of age (McGuiness, 2016). In 1933, the age of minimum age of criminal responsibility was set at eight for England and Wales and Northern Ireland. It was subsequently raised to 10 in 1963, but with the *doli incapax*¹⁰ principle protection for those under fourteen.

The James Bulger case, when two ten-year-old boys were tried and convicted of murder in 1993, exposed within the UK the dilemma of determining whether a child has capacity to understand the consequences of their actions. The Crime and Disorder Act 1998 removed the *doli incapax* provision soon after

¹⁰ Doli incapax means 'incapable of evil' meaning that under 14 a child was legally presumed to not know the difference between right and wrong.

(McGuinness, 2016). England is criticised for its low age of criminal responsibility (UN, 2007) and the Children's Commissioner and others have repeatedly pointed out that brain development and emotional and mental maturity of the child cannot be equated with that of an adult (Longfield, 2018: Longfield, 2016). Scotland has recently raised their age of criminal responsibility from age eight to age twelve (in 2019).

Research concerning the pre-requisites and pre-descents for criminal activity by young people particularly under the age of fourteen also indicates that criminality is often linked to situations of poverty, abuse and exploitation (Department for Education [DfE], 2015; McAra & McVie, 2010; Goldson, 2000). There is a certain irony that a ten-year-old is responsible for the consequences of their own criminal actions, despite mitigating factors - including their rights not been upheld for which adults are culpable. However, the fact that criminal legislation treats a ten-year-old the same as the twenty-four-year-old in terms of criminal responsibility, has implications for the argument against the gatekeeping that sometimes occurs around children's participation in decisions about their lives.

The Mental Capacity Act 2005 [MCA] protects the rights of people, age sixteen and over, to make decisions with the legal protection of the assumption that they have capacity to do so. The principles are as follows:

- 1) A person must be assumed to have capacity unless it is established that he lacks capacity.*
- 2) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.*
- 3) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.*

- 4) *An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.*
- 5) *Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.*

(Mental Capacity Act 2005, Part 1, Section 1)

The Deprivation of Liberties Safeguarding [DoLS] provision within the MCA exists to ensure that people without capacity are not restricted beyond that which is absolutely necessary for their safety or the safety of others (in line with Article 5 of the European Convention on Human Rights). However, until the Cheshire West judgment (P v Cheshire West and Chester Council and P & Q v Surrey County Council [2014]), the DoLS provision only applied to people aged eighteen and above, as parents were deemed to still have parental responsibility under the Children Act 1989 and 2004, and could agree for their child to be deprived of their liberties (supervised and restricted).

Since (the majority of) the Mental Capacity Act in England and Wales applies to young people over the age of sixteen, the Supreme Court decided that the safeguarding procedures should apply to those sixteen and above, apart from young people already under court orders (criminal). The line was drawn at sixteen years by the case *Re D (A Child; deprivation of liberty)* [2015] EWHC 922 (Fam) where the deprivation of liberties was challenged for a 15-year-old. The judge, Mr Justice Keehan ruled that because of the child's individual needs, the parents were justified as responsible parents for placing him in a restricted environment. He did note however that for a child of sixteen under normal circumstances to be placed in the same environment would be an "inappropriate exercise of parental responsibility" (Community Care, 2016). This clearly highlights how case law reflect some of the dilemmas particularly around the transition from child to adult. It also demonstrates how the tension of the rights

and responsibilities of parents and the rights of *disabled* children and young people may be viewed differently to non-disabled young people and their parents.

1.6 Children's Experience of Rights

As demonstrated, there is a tension between the element of age and maturity identified in Article 12, and the right to express and particularly the right for that expression to be respected; regard. Hart's ladder of participation (Hart, 1992) identifies the levels participation and impact of that participation for a child or young person. Hart's ladder is often used as a tool by researchers to pinpoint the expression and regard elements of Article 12 of the UNCRC when children and young people are involved in both research and observed in social care decision-making experiences (Brady & Franklin, 2019; McNeilly, Macdonald & Kelly, 2015; Murray, 2015; Cousins & Millar, 2007).

However, other examples demonstrate that professionals are influenced by other factors more readily than the children and young people themselves (Jones et al, 2012; MacDonald, 2013), or do not value the young person's voice in the facilitating of participation through appropriate support. This is particularly pertinent regarding disabled children and young people (Franklin & Sloper, 2008; Howarth, 2009) and has implications not just for the realisation of the rights of *participation* afforded by Article 12 of the UNCRC but for rights for child *protection* (Kennan, Brady, Forkan, 2017; McDonald, 2017; Franklin & Smeaton, 2016; Ferguson, 2016; McNeilly, MacDonald & Kelly, 2018).

Article 12 is not just concerning *individual* rights to expression, regard and support, but also indicates *collective* rights. Positive examples of children and young people involved in decision-making in government and policy include

research by Rome, Hardy, Richardson and Shenton (2015). However, the value of children and young people's participation may be tokenistic (Boylan & Darylmp, 2009; Murray, 2015). Participation can become meaningless, if there is no regard given to expression, or there is no support for expression – no voice or space (Lundy, 2007). This has been highlighted in several recent serious case reviews where children's voices have not been heard, and not regarded (Walters, 2019, Sidebotham et al, 2016).

1.7 Rights of Disabled Children and Young People

For disabled children, their capability is doubly questioned on the basis of their age and because of their impairment (Flynn & McGregor, 2017). Yet research has demonstrated that very young children and disabled children with complex communication needs are able to express views (McNeilly, Macdonald and Kelly, 2015; Underwood, Chan, Koller and Valeo, 2015; Georgeson, Porter, Daniels, and Feiler, 2014; Wickenden, 2011) and to ignore expression of views may have consequences for both provision and protection of children and young people (MacDonald, 2017; Cossar, Brandon, Bailey, Belderson, Biggart and Sharpe, 2013).

UNICEF supports a 'rights-based-social model' of disability for disabled children and young people (UNICEF, n.d.), and indeed the UNCRC expresses the application of all rights *without discrimination* to disabled children and young people. The argument that all rights are universal, is not necessarily negated by the fact that there is a distinct Convention for Children. Much of the UNCRC is concerned with protection, provision, and recognition of citizenship and relations with family unique to the chronological and developmental age of the person. However, the UN has found it a necessity to construct a Convention for

the Rights of Persons with Disabilities (UNCRPD) to address issues specific to disabled people. O'Brien and O'Brien (2000) note that:

‘The ‘label’/description of ‘disability’ is relevant only to the extent that the disabling condition complicates the fulfilment of [common human] needs’ (2000, p. 17).

A fundamental issue for disabled children and young people is that their rights as both disabled and as children fall between the cracks of these two conventions. Assurance of rights for this particular group of people is problematic in practice, not just in the UK but worldwide (Singal & Muthukrishna, 2014; Curran & Runswick-Cole, 2013; UNICEF, 2013).

For disabled children and young people, assumptions are not only made regarding their chronological age, but also about their understanding and capacity because of their “disability”. The acquisition of the right to participation and the degree to which a child or young person acquires those rights, could be subject to the willingness of people around them to support their acquisition of rights. Article 12 part two, clearly states the obligation to support the child and young person in expressing and being heard, and/or being represented in order that their participation is expressed. The acquisition of the knowledge of rights and the realisation of their right in participation becomes the result of the society around them imparting that right. However, as Article 5 of the UNCRC states this is the responsibility of parents and responsible adults around them to do so (Lansdown, 2010). It is to be noted that under the Children and Families Act 2014 (England), parents are included in decision-making for their children up to the age of twenty-five. Whilst there is a recognition of the principles of the Mental Capacity Act 2005, as with their non-disabled peers at the age of sixteen, the fact that parental responsibility extends to age twenty-five seems to ‘prolong’ the childhood of disabled children and young people.

Whilst rights of protection and provision are (arguably) *assured* through the ratification of the majority of the UNCRC within the UK through legislation, the reality for disabled children and young people is that rights are realised by individual children to different degrees and we return to the question of whether the right to participate is earned, acquired or assumed.

If rights in participation (Article 12) were truly assured, *all* children would be supported and regarded in their participation. The sticking point for the assurance of participation is the issue of regard given to the child's expression, by virtue of their age, maturity and capacity. Expression does not necessarily guarantee 'regard', however, as a founding principle of the UNCRC is of one of 'Best Interests'. Nevertheless, to dismiss the possibility of expression for disabled children and young people because of assumptions around their capacity and communication or lack of resources, does not uphold the other principles of the UNCRC of non-discrimination, nor does it conform to UNCRPD, Care Act 2014, Children Act 1989, 2004, Children and Families Act 2014 and Independent Reviewing Officer [IRO] guidelines regarding participation (DCSF, 2010). A child with complex communication needs should therefore be fully supported to participate in decisions about their lives, and importantly, regard given to their voice, however it is expressed.

To some extent the concept of rights of participation being *earned* could explain the historical approach to the treatment of disabled people and arguably is consistent with the medical model of disability. Under Gillick Competency¹¹ and Fraser guidelines¹², rights to determine one's own medical treatment (or not) are earned, by the fact that the young person has to demonstrate capacity. Young people over the age of sixteen, are assumed to have rights to make decisions

¹¹ Gillick Competency – ruling following (Gillick v West Norfolk, 1984) which meant that a young person under the age of sixteen was able to have contraceptive advice or treatment without their parent's consent if they were 'competent' to do so.

¹² Fraser guidelines -ruling following the Gillick case by Lord Fraser setting out guidelines for professionals regarding young people under sixteen and medical treatment.

under the Mental Capacity Act (2005), however, if it is doubted whether a person has capacity for that decision that has been made (MCA principle 1) the right to make a decision is technically *earned* through the Mental Capacity Assessment; proving that they have the capacity to make that decision even if it is an unwise decision (MCA Principle 4). Nevertheless, both the Care Act and the Mental Capacity Act are very clear that a person should be central to decision-making and be supported to participate, even if they lack capacity.

The expectation that a child has to 'earn' a right to express their view, is not consistent with the UNICEF and Children's Commissioners understanding of the rights to participation and begs several questions. If rights are to be earned, on whose judgement is this based on, and what mechanism is there for the justification of the child and young person not having rights to participate? If rights to participation of Article 12 are earned, there is a question as to what extent are disabled children and young people given support and opportunity to understand rights to be earned, particularly if they have complex communication needs. The realisation of the rights of disabled children can be viewed on the basis of *value* given to disabled children by society (Browne & Millar, 2016: Goodley & Runswick-Cole, 2014).

Concluding comments

As previously discussed, Article 12 indicates a judgement regarding capacity, maturity and age around the regard given to a child or young person's participation. However, the fact that children as young as 10 are held criminally responsible for actions of wrong they do because they are deemed to have the capacity to understand, indicates that rights and responsibilities may be *acquired* by virtue of age and appears to fly in the face of the argument that children do not have capacity to understand about issues regarding their care. Nevertheless, the lack of capacity to understand the full consequences of decisions should not

be prohibitive in the expression of views and due regard being given to that expression as agentic voice.

Returning to Walker's argument that rights are both *fact* and *process*, it can be seen that age, maturity and capacity are processes in the development from infant to adulthood. The element of *regard* could be argued therefore to also be a process, as it is somewhat dependent on these other variables and therefore acquired as a young person develops. The *regard* given to that expression is nevertheless governed by the 'Best Interest' principles and the duty of adults to protect. The UNCRC could arguably be interpreted to be pragmatic in its approach to children's' rights. The reality is that for professionals working with children and young people, decision-making is fraught with opposing tensions of risk and protection, choice and self-actualization (MacDonald, 2013; Kennan, Brady and Forkan, 2017). However, the right to expression, and right to support to enable that expression could be argued to be facts and are assured under the UNCRC. To 'support' in order to facilitate expression is therefore an obligation for all children and young people. Advocacy is a facilitating tool to support voice as the expression of a child or young person's lived experience in which their agentic wishes and feelings may be conveyed.

Chapter Two:

Communication and children and young people with complex communication needs

In the previous chapter, children and the concepts around children's rights and childhood were considered. Throughout chapter one, the rights of disabled children and young people were highlighted to be conceived and enacted differently compared to their non-disabled peers. This research is focused on disabled children and young people's participation; participation being a right afforded to them through the UNCRC - particularly Article 12. Before considering advocacy as a tool for participation in chapter three, attention will turn towards communication and the voice of disabled children and young people. Advocates should be in a position to understand, or at the very least have an awareness of, communication of the children and young people with complex communication needs with whom they work. Therefore, this chapter considers a crucial theme of this thesis.

The first part of this chapter will focus on understanding of the communication of children and young people with complex communication needs. Attention will then turn to the evidence of children and young people with complex communication needs in participation in decision-making and in research, reflecting on Lundy's four factors of participation of 'space, voice, audience and influence' (Lundy, 2007).

2.1 Understanding communication with children and young people with complex communication needs

Much of the research around communication and communication development is based on typical language development of babies and children without disabilities. However, it should be noted that atypical language acquisition and difficulties in pre-verbal communication development can be present in children with autism (Bogdashina, 2004; Caldwell, 2012) for example, and reduced eye contact, crying or making noises are common in children with Angelmann syndrome for physical reasons (Dan, 2008). Therefore, caution must be taken to avoid negating atypical communication means and/or development (Petry & Maes, 2006; Hannon & Clift, 2013; Dan, 2008).

Historically the expectations of communication development for children and young people with complex communication needs was minimal (Aird, 2013). However, following the Children Act 1989 and the National Curriculum being accessible and a right for *all* children, schools in England have used P-levels (Pre-National Curriculum levels 1-8) in an attempt to categorise and to measure progress in National Curriculum subjects, including language development. There has been criticism of P-levels, as the focus is on the measuring and 'standardising' of attainment rather than individualised and child-centred learning and progress, particularly for children with complex needs. They have recently undergone revision following the Rochford Review 2017 (DfE 2017).

Attention will turn to the understanding of expression or communication of children and young people with complex communication needs. This is important, as understanding a child or young person's *expression*, should lead to

appropriate *support* and therefore *regard* for that individual's expression. When considering communication or expression, there are three main themes identified from the literature. *Means, intent and context*. These will be briefly considered before attention to issues identified with coming to a consensus as to the meaning of the individual child or young person's communication.

Means of Communication

There are many different forms of communication other than verbal communication including vocalisation, facial expression, gesture and avoidance (Caldwell, 2012; Bunning, 2004). These are commonly used and understood, although with variances within different cultures (Ross, 2011). For children and young people with communication needs, developing communication may take alternative forms.

When speech communication is aided or supplemented, it is referred to as Alternative and Augmentative Communication [AAC]. AAC can be 'low-tech' - such as gesture or 'Signalong' signing (Scott, 2001), or more 'hi-tech', such as the use of iPads. Frequently children and young people will be encouraged to use a range of AAC - for example combining gesture and Picture Exchange Communication System [PECS] to communicate (Charlop-Christy et al, 2002). Use of AAC can be used to support communication development but Ogletree, Bruce, Finch, Fahey, and McLean (2011) also advises that any AAC need to be appropriate and meaningful to that individual. Light and Drager (2007) also suggests that a young child has to negotiate not only the activity and the person attempting to communicate with them, but also the AAC itself which may demand eye-gaze or deliberate physical movement that may offer a challenge to them. I have observed in my advocacy practice a whole array of AAC's in use but am also aware that the instigation of the initial use of 'object' AAC's is by another - not the child or young person themselves. Yet I also know many children, young people and adults with complex communication needs develop their own

gestures and it is others around that have picked up on a particular movement and associated it - given it meaning.

Intensive interaction is based on the early stages of language development (Goodwin, 2013; Hewitt & Nind, 1998). It focuses on interaction between the carer or practitioner and the individual for itself through mirroring the child's own behaviours, rather than as a means to achieve an outcome or learning. Goodwin (2013) sees intensive interaction as a means to enter the world of and thereby develop a shared code of meaning through reflection by the practitioner. It therefore gives agency and 'voice' to individual who may be perceived as having pre-intentional perlocutionary communication (Caldwell, 2012). Doak (2018) studies the use of AAC and intensive interaction in schools with children. She found that child-led intensive-interaction sessions *alongside* the experience of learning shared communication such as PEC's in teacher/adult-led activities was meaningful and supportive of the individual children's communication development.

Intention of communication

Some children may be able to verbalise, but their understanding of language may be compromised (Hannon & Clift, 2013; DeVito, O'Rourke, & O'Neill, 2000) and many children and young people with complex communication difficulties may be non-verbal. McLean and Snyder McLean's (1998) communication descriptors of 'perlocution', 'illocution' and 'locution' are commonly recognised in speech therapy circles to describe levels of *intent* of communication for individuals with 'severe learning and complex disabilities' (Ogletree, Bruce, Finch, Fahey & McLean, 2011). In brief, within the 'perlocutionary' category, individuals do not appear to communicate with intention, but can be reactive to situations. Within the 'illocution category', individuals appear to have *some* intention of communication, such as eye gaze, gesture and may understand symbols in

context. ‘Locutionary’ communicators are able to use symbols, signs or movements to communicate intention.

I am cautious to ‘label’ and categorise, however, *intention* may be a factor for advocates to consider for children and young people they are working with. This is particularly important in the understanding of instruction and ‘non-instruction’.

Context of Communication

Understanding of the intent or meaning of communication can be influenced by the *context* of communication. Simmons and Watson’s case study (2010) focused on the issues of co-construction and attributing meaning to non-verbal communication in relation to one child, Sam, who is observed in two settings over a period of time. Sam’s behaviour is observed, described and interpreted differently by staff in one setting compared to the other. Greathead et al’s (2016) case studies to research the support for children with complex communication needs also indicates that relationship and activity can influence the level and intensity of communication by a child. ‘Evie’, for example, interacted more readily with certain activities, and more often with certain people, such as her grandmother, than with others. It is important to recognise that individual children and young people’s communication levels and means may fluctuate within different contexts, but also as consequence of the underlying condition affecting their communication (Bunning, 2004) or a response to something being amiss - such as pain (Solodiuk, 2013).

Receptivity to communication

Communication is dependent on a receptive environment according to Kelly’s ‘effective communication model’ (Kelly, 2010). For children and young people who have complex communication needs, ‘relaying meaning’ may be more

complex. Receptivity is essential for the child or young person's expression to be received. However, frequently a child or young person's attempts at communication are not received. This has consequences in the suppression of the agency of the child or young person (Nind, Flewitt & Payler, 2010). Receptivity and reciprocal interaction are suggested to be linked to familiarity with the child or young person, but also to the training and experience of the adult receiver by Greathead et al (2016), although not explored within their study.

Consideration also must be given to the attitudes and willingness of others to be receptive to the action/method of their communication. The participation of disabled children and young people can be hindered by a lack of recognition of agency and voice (Tisdall, 2012; Wickenden, 2010). Low expectation and negative attitudes have been identified as one of the barriers to disabled children and young people with complex communication needs participating in decision-making or research (McNeily, McDonald & Kelly, 2015; Liddiard et al, 2019; Greathead et al, 2016; Mitchell et al, 2009; Nind, Flewitt & Payler, 2010). Yet there is growing evidence of meaningful participation of young disabled children and young people through the use of appropriate communication tools and receptivity to children and young people's 'voice' (Underwood et al, 2015; Georgson et al, 2014; Wickenden, 2011). Shulmann (2009) refers to reflecting in preparation for communication, as "tuning in"; taking time for "preparatory empathy" before meeting in order to understand possible issues and barriers to their communication. This may be significant in advocates' practice to be aware of their own receptivity to a child or young person's communication.

Consensus of meaning of an individual's expression

Communication itself is interaction between the individual and, at the very least, others within the child or young person's microsystem. Deciphering accurately and consistently is a challenge for people working with and around a child or

young person with complex communication needs. Bunning (2004) points to the difficulties of inadequate development of the 'shared code' in communication with people with complex communication needs; there is a difficulty in the 'construction of meaning'. Grove, Bunning, Porter & Morgan (2000) identify various "indicators of communicative intent". These include not only using eye gaze and gesture, but also movement of self towards another and changing behaviour to elicit response. Some methods of communication may be difficult to understand and maybe challenging for those around the child or young person (Caldwell, 2012; Goodwin, 2013; Hannon & Clift, 2013), particularly if it involves behaviours that are perceived to be self-injurious, destructive, noisy and repetitive for example.

Various studies have attempted to profile expressive communication of individuals with complex communication needs through consensus between those involved in their care, including parents (Solodiuk, 2013; Petry & Maes, 2006). Yet non-verbal communication is often interpreted through tacit intuition rather than explicit knowledge (Phelvin, 2012). Phelvin (2012) further builds on Kinsella and Whiteford's concept of 'reflective practice of epistemic reflexivity' to examine other influences within oneself affecting the interpretation of the non-verbal communication (Kinsella & Whiteford, 2009). It appears that whilst 'knowing' a person may be seen as an advantage to understanding individual communication, having an open mind as an unfamiliar observer, may have advantages in that preconception and prejudice through over-familiarity may be avoided (Lyons, 2003). This has implications for the practice of advocates and for researchers with children and young people with complex communication needs attempting to understand a child or young person's communication. Whilst they may communicate by necessity with others, their own observations are valid too, and may provide useful, previously un-noticed insights.

2.2 'Value' of 'voice'; disabled children and young people as participants

In the previous chapter, disabled children and young people rights were discussed and the discrepancies in enactment of their rights compared to their non-disabled peers were highlighted. Recognising and supporting the voice of disabled children and young people is key to participation in order to realise rights. Therefore, attention will now turn to the abling or 'dis-abling' of voice and agency of disabled children and young people with complex communication needs.

The expectation of all children and young people to follow a linear developmental path and communicate in a standard way could lead to the assumption of the medical model of disability for those children and young people with complex communication needs; if a child and young person cannot communicate in speech, they need to communicate in a standard way to be understood by the people. Whilst I have outlined communication descriptors and recognised communication tools such as picture exchange communication [PECS] which enable children and young people to communicate in different ways, my intention is not to assume a medical model. Eddie spent hours being 'taught' to read, yet Eddie was not able to understand the concepts of the words in front of him. Being 'normalised' I can understand was important for my aunt and uncle at the time in the context of their situation, but I can also understand the negative impact on Eddie. Certainly, Augmented and Alternative Communication methods enable a much wider range of communication for disabled children and young people. If Eddie was a young child now, I would hope that he would have been able to access and utilise some method that would have worked for him. Facilitating AAC however, is reliant on society funding the necessary resources and training.

The issues surrounding the desirability of encouraging the use of standard versus non-standard communication methods is beyond this research. Tapping into the intention of communication by others can be a challenge. Nevertheless, the use of 'intensive interaction' and recognising that children and young people may develop their own communication methods, supports the agency of children and young people in communication (Goodwin, 2013; Caldwell, 2012) and implies an affirmative-social model of disability (Swain & French, 2000). Disabled children and young people with communication needs have the same rights to be participants in decision-making as their non-disabled peers, and it is the enactment of this right in the circumstance of their communication needs that remains the focus of this research.

I do not consider that rights of participation, agency or voice of disabled children or young people should be regarded as different to their non-disabled peers. But, the assumption of 'verbal voice' as the tool to demonstrate agency risks excluding non-verbal disabled children and young people in participation through by ableist and adult thinking (Stafford, 2017; Tisdall, 2012). Research has demonstrated time and again, that the voices of disabled children and young people can be lost, ignored, unsupported, and crucially not acted upon (Liddiard et al, 2019; Greathead et al, 2016; McNeily, McDonald & Kelly, 2015; Nind, Flewitt & Payler, 2010; Mitchell et al, 2009; Knight & Oliver, 2007).

Many social workers do not include learning disabled children in decision-making and much of this is to do with *confidence, experience and skills* in communication (Kelly, Dowling & Winter 2015). This is supported by the more recent findings of Prynallt-Jones, Carey and Doherty (2018), who indicate that funding resourcing and training impact on social workers ability to communicate, despite willingness and creativity. Furthermore, the Children's Commissioner for England also has highlighted the issue in recent reports (Longfield, 2019, 2018), with children and young people not able to access communication tools or professionals who are

able to understand their individual communication. Children and young people are therefore not only at risk (Stalker & McArthur, 2012) but are ‘dis-abled’ by lack of provision to enable them to express; to have ‘voice’. This is discriminatory and contrary to the principle of non-discrimination set out by the UNCRC, and in breach of the CRPD (Longfield, 2017).

Whilst individuals may not be intending to discriminate on the basis of communication needs in the enactment of the right of participation, there is evidence that disabled children and young people, particularly those with complex communication needs are not being involved in decision-making processes because of the *attitudes* of the social workers and other professionals and parents involved in their case (Stalker & Connors, 2003; Kelly, Dowling & Winter, 2018). A disabled child’s voice and agency is impacted by the power dynamics of being both child *and* disabled (Stafford, 2017; Tisdall, 2012). Adults acting as gatekeepers (Knight & Oliver, 2007; Kelly, 2005) effectively give no value to the participation of, and arguably the rights of, those children and young people with complex communication needs (Michell, 2007; Franklin & Sloper, 2009; Stalker & McArthur, 2012).

The participation and voice of disabled children and young people with severe and profound learning disabilities who communicate at a perlocutive or illocutive level (see Ogletree et al 2011 outlined in 2.1), can be hindered by the lack of recognition of ‘agency’ (Wickenden, 2019). Several researchers in the field of research with children and young people with learning disabilities have utilised the capabilities frameworks of Nussbaum (2006) and Sen (1985) (see Hart and Brando, 2018; Biggeri, 2007; Underwood et al, 2015) to position agency and voice of children and young people, including disabled children with complex communication needs. Browne & Millar (2016) apply Nussbaum’s (2006) ten capabilities to agency of disabled children, focusing on individual uniqueness. They see capabilities as complimentary and an extension of ‘voice’. They extend their argument to demonstrate that agency and the voice of personhood is not

just individualistic but based on social and relational understanding of both what is, and value attributed to, being ‘human’.

This argument is also made by Goodley and Runswick-Cole drawing on the philosophical arguments around what is understood by being normative human and dis/abled (Goodley & Runswick-Cole, 2016). In a world where ability, power and strength are prized, there becomes a binary of have, have not, achieve, not achieve, abled and dis-abled and arguably human and non-human (Carlson and Kittay, 2010). Yet the rights afforded by UN are not dependent on ability or achievement, but on the fact of ‘being’. The right to participate, to be protected and provided as a child is without discrimination. Nevertheless, hearing the voices of disabled children and young people with severe and profound impairments and complex communication needs and enacting their rights is not just dependent on the *understanding* of individual expression. It is impacted by attitudes towards the agency and voices of disabled children and young people and *valuing* them as equal to their peers. If we consider that voice is the expression of a child or young person’s lived experience in which their agentic wishes and feelings may be conveyed, not hearing those voices, whether through practical or attitudinal reasons, risks not affording *value* to their lived lives and thereby de-humanises the child or young person.

Conceptual Framework for understanding ‘voice’ for disabled children and young people with complex communication needs.

The concept of ‘voice’ was established in the Introduction, and in this and the previous chapter, consideration has been given to the rights, and the actualization of the rights of voice, for disabled children and young people with complex communication needs. In this section, a conceptual framework around participation and value for the voices of disabled children and young people with complex communication needs is introduced.

In the previous chapter Lundy's four factors of 'voice, space, audience and influence' (Lundy, 2007) were discussed in relation to the three elements of Article 12 namely *expression*, *support* and *regard*. Lundy does consider that the factors of 'space' and 'voice' for a child or young person's expression can encompass non-verbal communication and expression in other forms. Yet as demonstrated above, the extent to which *disabled* children and young people's voices, particularly with complex communication needs or expression, is considered as valid as their non-disabled peers is debateable from the evidence of critical disabilities studies and disabled children's research literature. Lundy's factor of 'influence' is impacted by the extent to which agency and voice are recognised. Regard for expression can be 'value'-based through conscious or unconscious bias¹³, particularly for children and young people who may not be able to verbally articulate and for whom support to express maybe be costly and time consuming. I therefore propose that the 'value' given to the child or young person's 'voice' should also be considered a factor, particularly towards disabled children and young people with complex communication needs.

The three elements of Article 12 are intertwined. *Regard* in the form of 'audience' and 'influence' for a disabled child or young person's voice has to be considered in the context of the attitudes and 'value' placed on their 'voice' as disabled children and young people with complex communication needs in the first place. Without value- recognising the agentic voice and taking regard of the child or young person's agency, a child or young person's *expression* can be hampered by lack of provision of *support* or 'space' and consequentially, there is little hope for *regard* for the child or young person's agentic expression or voice.

Figure 1 illustrates the relationship between '*expression*, and *support* and *regard*' elements of Article 12 and factors in the realisation of the

¹³ Unconscious bias refers to learned stereotyping that is automatic and unintentional.

rights of article 12 outlined by Lundy (2007). The straight black arrows reflect that support enables expression, and support also can enable regard. Support may not be necessary however, but support in the wider sense of Lundy's factors is a provision to enable expression to be regarded. The curved arrows around 'voice', 'space' and 'audience' reflect that the relationship between these factors is fluid – the opportunity, facilitation and being listened to are dependent upon both the giver enabling, and also receiving. Only after a child or young person's voice is facilitated and listened to through space and audience can influence of the voice be activated. This will be further discussed in Chapter two.

The additional factor of 'value' links expression- 'voice' and regard, as I consider that 'value' plays an important role in whether a disabled child or young person's expression or 'voice' is given 'space' and 'audience' in order to 'influence'. This will be further discussed in light of the findings of my research. Figure 1 is in effect a conceptual framework for my research findings.

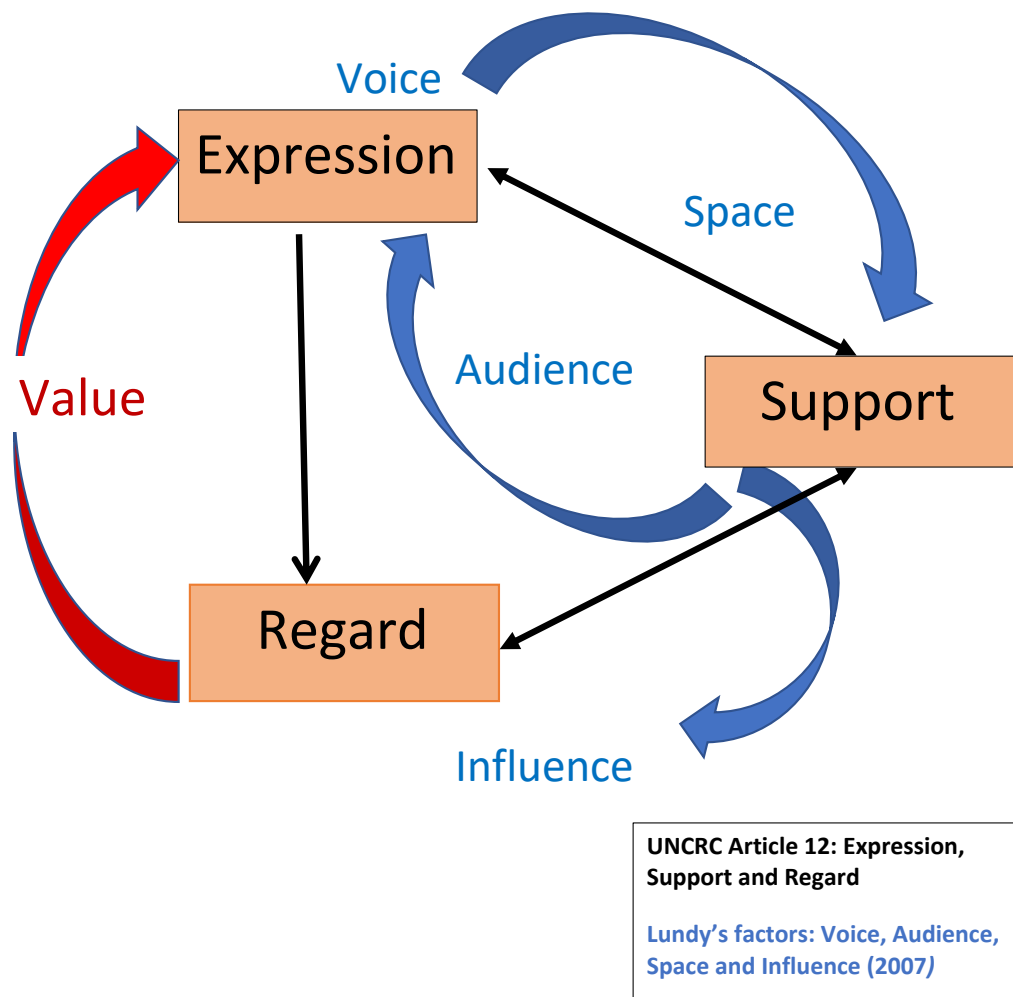


Figure 1: The relationship between the elements of UNCRC Article 12 Lundy's four factors of participation and value given to a child's participation

Concluding comments

Whilst this research is particularly focused on children and young people with *complex* communication needs, speech and language and communication difficulties are common within the general population of children and young people in this country. Over 10% of all children and young people have speech,

language and communication needs, with 2.3% of all children having speech and language needs in conjunction with other difficulties such as hearing impairment or autism (Bercow, 2018). Advocates are likely to encounter children and young people with a range of speech and language and communication needs particularly given that 60% of young offenders and 81% of children with emotional behavioural disorders will have language difficulties (Bercow, 2018), and statistically these children are more likely to be found within the care system (Longfield, 2016). Resourcing and funding for speech and language has been cut in recent years, and this will impact on all children with speech and language communication difficulties, including children and young people with *complex* communication needs.

In this chapter, I have outlined communication and the importance of *means*, *intent* and *context* of communication for children and young people with complex communication needs. The issues of coming to a consensus of understanding communication with others has been discussed, as has the importance of a receptive environment for children and young people's expressed communication to give voice and support agency.

Communication, speech and language development and forms of non-verbal communication are vast topics, and I am conscious that I have only been able to 'scratch the surface'. Yet I regard, for advocates, *an* understanding of a child or young person's 'expression' is essential to be able to 'support' a child or young person's agentic voice. This chapter is a 'bridging' chapter between laying out the rights of children and young people in the previous chapter and exploring advocacy as a tool of support for the realisation of those rights in the following chapter.

Chapter Three:

Advocacy as a Tool for Participation

Attention will now turn to advocacy and its role as a tool for support for 'voice' in the realisation of the rights of a child or young person, particularly in relation to participation. As with chapter one, the historical, social and theoretical contexts of concepts are important to consider. The purpose and practice of advocacy in the UK is diverse, but attention will mainly focus on children and young people from age nought to twenty-five (the age for disabled young people covered by the Children and Families Act 2014), in particular, independent advocacy. Advocacy as a discrete provision in England has largely derived from social work practice, which in itself has a history, and there is much overlap. Social work theory is considered briefly before systems theory as a theoretical framework for this research is discussed.

This chapter is divided up as follows:

3.1 Advocacy Definition

3.2 Advocacy: Practice and Purpose in Social Care

3.3 Development of Advocacy in the UK

3.4 Types of Advocacy in England

3.5 Independent Advocacy for Children and Young People

3.6 Development of Theory of Advocacy

3.7 Systems Theory as a Theoretical Framework

3.1 Advocacy definition

The origin of the word advocacy comes from French verb *avocacie* as ‘*the act of pleading for, supporting, or recommending*’ (The online Etymology Dictionary, 2017) derived from the Latin *advocare* which is the verb to ‘*summon, call to one's aid*’ (Oxford Dictionary, 2017). It is easy to see from the broadness of the term, how practice and therefore understanding of the use of the term ‘advocacy’ and its definition might be difficult within the modern social care context. Anecdotally, when working as an advocate, I learnt very quickly to qualify my role as a “Social Care Advocate” after having to explain that, whilst I did know a little about law and I worked within legislation, I was not legally trained: my job was to help people have a say in their care/social care, not to stand up in courts. The confusion and association of the term advocate in legal sense is not surprising, since it is indeed the title of a legal professional in practice.

It should be noted also that “advocacy” is a term that can be applied to other causes such as consumer rights, animal-rights, saving forests (world advocacy.com, 2017). Human Rights and use of advocacy for LGBT+, ethnic minorities, or women’s rights for example, encompass disabled people and other “people who access social care” (National Development Team for Inclusion [NDTi], 2016) and vice-versa. My focus will remain on the definition within the context of “people who access social care”.

Defining “Advocacy” appears to be the first obstacle for the few academic writers on the subject. Dalrymple & Boylan (2013), Wilks (2012), Brandon & Brandon (2001), Henderson & Pochin (2001) all cite the difficulties in adequately describing advocacy purpose, process and outcomes.

Brandon & Brandon (2001) define advocacy thus:

Advocacy involves a person, either a vulnerable individual or group or the agreed representative, effectively pressing their case to

influence others, about situations which either affect them directly or, and/or more usually, trying to prevent proposed changes which will leave them worse off. Both the intent and the outcome of such advocacy should increase individuals' sense of power; help them to feel more confident, to become more assertive and gain increased choices. (Brandon 1995, p. 1 cited Brandon & Brandon 2001, p. 20)

Wilks (2012) examines these definitions, and that of Thompson (2002) linking advocacy and empowerment. Wilks suggests that as well as advocates representing views and being involved in persuading others or giving voice, there is “an important emotional and psychological component in advocacy” (2012, p. 3). Macadam, Watts and Greig (2013) in their scoping study of services cited the definition used by advocacy agency representatives, in other words, self-defining by the advocacy agencies themselves:

“Taking action to help people say what they want, secure their rights, represent their interests and obtain the services they need”. (from Action for Advocacy Macadam et al 2013, p. 4)

Henderson and Pochin (2001) take the definition of advocacy further:

*Advocacy can be described as the process of identifying with and representing a person's views and concerns, in order to ensure enhanced rights and entitlements, **undertaken by someone who has little or no conflict of interest**. (Henderson and Pochin, 2001, p. 1) (bold my emphasis)*

The phrase ‘undertaken by someone who has little or no conflict of interest’ is particularly important to highlight especially for disabled young people being advocated for by their parents – a provision under the Children and Families Act 2014, and sometime assumed under the Care Act 2014. Whilst acknowledging the significant roles of parents and carers in advocating, the focus of this thesis concerns ‘Independent Advocacy’ as a significant right for all children and young people, including disabled children with complex communication needs. However, it is important to examine advocacy in its wider context, and thus the purpose, history and practice in the broader sense will be examined before

focussing again on Independent Advocacy in the context of health and social care, specifically for children and young people with complex communication needs.

3.2 Advocacy; practice and purpose in social care

Brandon & Brandon (2001) state that advocacy, in the sense of speaking out on behalf of another, has been part of human behaviour evidenced in many historical texts and stories; the development of advocacy in the *context of social care* is linked closely with the history of *social work and social justice*. (Brandon & Brandon, 2002, Boylan & Dalrymple, 2013; Wilks, 2012). For example, Elizabeth Fry's work with female prisoners, advocating for better conditions, protection for the children, and encouraging self-advocacy. The work of the well-meaning and "enlightened" such as members of the Fabian Society and the Charity Organisation Society to alleviate poverty and support the vulnerable in society, are examples of social work and advocacy work in practice within the 19th century (Jones, 2002). The Settlement Movement (envisioned in 1884) took a step further towards self-advocacy through community development, which then led to the establishment of Legal Aid (Wilks, 2012). Notably the early social work educator, Eileen Younghusband, exemplifies both in her work and writing "*how advocacy historically has been associated with and been a core part of social work*" (Wilks, 2012, p. 8).

Whilst Wilks (2012) considers the role of social workers important in supporting self-advocacy in their practice for both groups and individuals, it is widely recognised that advocacy within social work practice has limitations, particularly when it comes to people who are not able to self-advocate and for whom decision-making is either difficult or contrary to what a social worker considers to be in their best interests (Dalrymple & Boylan, 2013; Wilks, 2012; Brandon &

Brandon, 2001). Nevertheless, advocacy is not confined to the field of social work. Dalrymple & Boylan (2013) explore the use of what they term “internal” advocacy, speaking out on someone's behalf often carried out by social workers, youth workers, nurses or teachers. They consider that this can be done formally or informally as part of their professional duties. Evidence of practice can be found in education (Ng et al 2015), psychology (Routh 2005) and the Nursing and Midwifery Council (NMC 2008; Bateman 2000). Indeed Towley (2014), Children’s Commissioner for Wales, calls for the advocacy training of teachers and youth workers alongside provision of independent advocates.

Whilst the focus of this thesis is the practice of advocacy within the UK, advocacy is evident world-wide. For example, advocating in mental health services for individuals has been recognised in Western Europe and North America for many years (Fontaine & Allard, 1997). Independent advocacy for children and young people in Family Group Conferences (child protection) familiar in the UK is also used in New Zealand and Canada (Fox, 2018). Disabled children and young people are not so visible in advocacy world-wide, although there are examples such as Disability Africa which advocates for the rights of disabled children and young people whilst supporting them and their families in communities to access resources where statutory services for disabled children and young people are scarce (Disability Africa, 2018).

Advocacy with (adult) disabled people and people with learning disabilities nevertheless is evident world-wide such as in the work of ‘African Association of Disability and Self Advocacy Organisations’ and ‘Africa Disability Alliance and European Disability Forum’. However, the emphasis is often on collective and systemic advocacy to challenge systems rather than on advocating on an individual basis (AADSAO, 2015; EDF, n.d.). Advocacy, empowerment and education can work hand-in-hand to promote rights and challenge inequalities around the globe and challenge inequalities. The Disability Advocates project for example trains advocates and disabled people in the EU, Iceland and Norway,

Bulgaria, and Romania around rights-based legislation particularly regarding employment issues (DARE, n.d).

In the UK, it could also be argued that the adoption and specific use of the particular word “advocacy” applied to working with disadvantaged groups and individuals *within* the social care system as opposed to advocacy *for* a social care system is a relatively new development, as is the development of a social care system itself. There has been a shift from the era of workhouses, through Stanley Baldwin's Local Government Act (1929), to the post Beveridge Report era of the Welfare State and to the closure of large hospital/asylums institutions in the 1980s. From the situation where social care charities and social workers both advocated to change policy and provided care for individuals, there has been a shift to government agencies (NHS/Adult or Children’s Services) controlling the provision of care. Specialist advocacy agencies have emerged to advocate for cases *within* the centralized provision and professional social work practice.

Continuum of Practice?

New Zealand Health and Disability Advocacy (Drage, 2012) discuss various models of advocacy practice and suggests that advocacy practice could be described as being on a continuum of practice. They consider advocacy fitting a continuum of *influence* and on a continuum of *empowerment*. Wilks (2012) also suggests dimensions of advocacy in *purpose, perspective, focus and scope*. Considering advocacy practice on a continuum can aid to both map and include the various types of advocacy practice seen in the UK.

important to recognise advocacy operates on a similar basis to other countries such as New Zealand (Drage, 2012). Advocacy is also part of, and also distinct from, social work across the world.

The common factors in the history and the current advocacy practice are:

- 1) Rights – recognition, upheld
- 2) Standing *for* or *with* or *behind*
- 3) Case or cause - injustices challenged

3.3 Development of Advocacy in the UK

Advocacy in the field of disability is key to this thesis and it is therefore important to briefly sketch the history of the changing attitudes and beliefs around disability that has impacted on, or been impacted by, advocacy working with disabled people. The terminology around disability historically in some degree reflects the attitudes and perceptions of society (Chapman, Mitchell, Ingham, Ledger, Traustadottir, 2006; Gray & Jackson, 2002).

Oliver's work and subsequent academics and disabled activists such as Tom Shakespeare and Dan Goodley, have challenged the traditional view of a person being disabled and medicalizing a condition that the individual needs to overcome or address. Oliver (1983) suggested that disability be seen within the context of the societal barriers and inequalities towards difference and impairment. This has become known as the social model of disability. There has been much debating and counter-debating around the social model (Connors & Stalker, 2007; Baker & Donnelly, 2001; Swain & French, 2000; Shakespeare & Watson, 1997). Whilst disabling factors can be addressed by society, so that equality of opportunity and access is possible in many cases, Swain & French

(2000) and others argue that it must be acknowledged that the social model of disability is not easily applied to people with the most complex of needs. Nevertheless, the social model of disability and its significance to the rise of self-advocacy in particular, and impact on Disability Rights, and emancipatory social work cannot be overlooked.

The emergence of asylums and hospitals, the forced sterilization and segregation of the “defectives” is well documented and critiqued (Chapman et al, 2006; Gray & Jackson, 2002). The move towards closure of large institutions could be linked to the greater awareness of human rights post-war and the rise of the Independent Living Movement (Wilks, 2012) and People First in the 1980s (Chapman et al, 2006). Although policy change to practice change took over fifty years (Chapman et al, 2006) and there are still remains issues with ‘out-of-area’ institutional provision for people with complex needs as highlighted in Flynn report (Gloucester SCR, 2012) post the Winterbourne View scandal, and in the Lenehan report ‘These are our children’ (Lenehan, 2017).

Social awareness and eventually the will to change policy and practice towards the care of disabled people is demonstrated in the Valuing People (2001), Valuing People Now (2007) reports around people with Learning Disabilities [preferred term], alongside the Disability Discrimination Act (1995) and the subsequent Equality Act (2010). Views of disability and society’s response have shifted, and, Oliver's seminal work (1983) on the individual and social models of disability became, in his words:

“the vehicle for developing a collective disability consciousness helped to develop and strengthen the disabled people's movement that had begun to emerge a decade earlier”.

(The Social Model of Disability: 30 years on. Mike Oliver 2013
Disability and Society 2013 volume 28 No.7, p. 1024)

Agencies within the UK specifically set up to advocate within social care have only emerged in the last twenty to thirty years within the voluntary sector with both paid and unpaid advocates. Whilst social work training has been in existence for many years, Social Work as a profession and recognised qualification leading to a protected title through registration, has only been in existence since 2000. The chronology is important to acknowledge.

Dalrymple & Boylan (2013) in relation to children's advocacy point out correlation between the rise of professional advocacy and the diminishing advocacy role undertaken by social workers within the UK. Advocacy is very much part of social work practice worldwide (International Federation of Social Workers IFSW). However, within the UK standards of practice, referral to independent advocacy is a requirement of good practice when there are potential conflicts of interest and to ensure service user voice (*Professional Capabilities Framework for Social Workers* PCF 4 (HCPC, 2012)). UK social workers are less involved in the emancipatory advocating actions akin to their overseas peers. Advocacy has become more separated from social work practice to become a distinct role within social care.

Figure 4 charts the historical context of advocacy development in the UK.

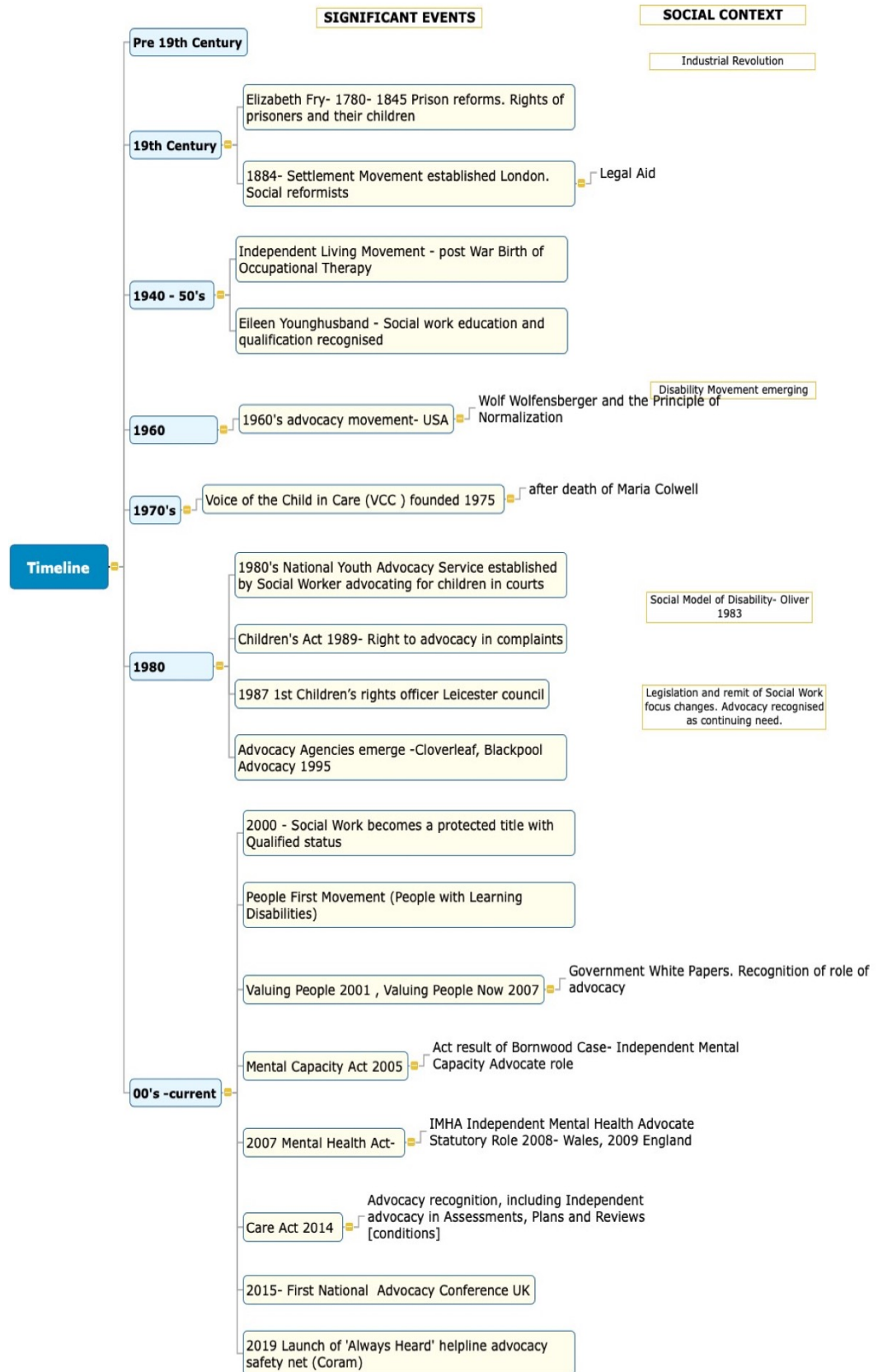


Figure 4 Timeline of advocacy development in historical context

3.4 Types of advocacy in England

Having discussed the social and political context of the development of advocacy and the concept of advocacy working historically, attention will now turn to the current spectrum of advocacy working within the UK. Macadam et al's scoping of advocacy agencies (2013) and Stewart & Macintye (2013) confirms that there are several types of advocacy within the UK within the social care sector commissioned by local authorities.

Table 1 summarises the different forms of advocacy in England.

Advocacy		Features	Potential issues
Self-Advocating	Self-Advocacy-group	Formal or informal Advocacy agencies often facilitate groups. Members can contribute to local authority Partnership boards	Tokenistic Facilitators can lead rather than encourage self-led groups
	Self-Advocacy-individual	Issue – based Can be a result of previous advocacy support. Advocating for self	Effectiveness depends on circumstance
Voluntary Advocacy	Citizen Advocacy	Unpaid volunteer- either issue based or long –term befriending. Can take on wider support role than paid advocate	Training and continuity
	Peer Advocacy	Person with similar experience advocates with person. More common in Mental Health Advocacy	Can be effective support, but potential issues around boundaries for peer
	Family and/or unpaid carers	Family members or friends or unpaid carers supporting for person to be heard Parents often advocate for their children Role under Care Act	Conflict of interest? Support for family/carers is available
Professionals as Advocates	Social workers, teachers, nurses, paid carers or other professionals	Professions other than advocates advocating as part of their profession Social workers historically have advocated for the people they work with	Conflict with other role. Not seen as Independent

Independent Advocates	Generic	Advocacy for people who are not eligible under legislation for advocacy support – such as parents going through Child Protection	No legislation. Funding subject to local authority commissioning
	Health Complaints	All ages under the Health and Social Care Act 2012	Access to service for children and young people?
	Children and Young Persons Advocate	The Secure Training Centre Rules 1998 (children detained) The Children's Homes (England) Regulations 2015	Access Commissioning service- potential issue of impartiality (Medway SCR 2019)
	Independent Mental Capacity Advocates (IMCA)	Referral for those who lack capacity for specific (limited) decisions following a Capacity Assessment Applicable age 16+ The Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (General) Regulations 2006	Short time allowed Best Interests not necessarily wishes Dependent on SW referral after a Mental Capacity Assessment regarding specific decision Can work alongside generic or Care Act Advocate
	Independent Mental Health Advocates (IMHA)	Advocacy for people (all ages) detained under Sections of the Mental Health Act 2007 Provision whilst in hospital – usually by visiting advocacy	Limited to those under section, although many advocacy agencies also cover voluntary patients as well

		service. Support in reviews etc.	
	Care Act (2014) Advocacy (England)	<p>Independent Advocacy for age 16+ with no appropriate unpaid advocate</p> <p>If person has 'substantial difficulties' in understanding, retaining processing and communicating information and wishes for certain assessments and reviews</p> <p>Commissioned service</p> <p>Specifies role of advocate to support voice of person</p>	<p>Recent advocacy provision. Uptake inconsistent across England</p> <p>Confusion as to understanding of "substantial" difficulties</p> <p>Conflict with family? Issue of terminology around who is an appropriate person</p>

Table 1 Summary of the different forms of advocacy in England.

Self, Peer and Group advocacy

The concept of self-advocacy as being able to advocate oneself is arguably the ultimate goal of advocacy practice. Often self-advocacy on an individual basis is around a specific issue. Collective advocacy is self-advocacy taken on by groups rather than individuals and moves towards advocating for, advocating on behalf of a cause or for general issues pertinent to a particular disadvantaged group of society. Goodley (2004) indicates that there is a direct relationship between the lack of opportunities for minority groups which makes the need for self-advocacy a result of culturally created deficiencies. There are various models of collective advocacy (Macadam 2013, Boylan & Dalrymple 2009), and, for example with Learning disability groups, there are often attenders of the group in an "advisory"

role. But this is not without some concerns; agendas are not always defined by the group members, but by their well-meaning supporters (Goodley 2004, Williams 2006). Boylan and Brave (2006) question whether for children and young people, self-advocacy both on an individual or collective basis, is regarded as a token gesture by adults to appease rather than to give real voice to children and young people. Certainly, this concern is echoed by the findings of Murray (2015).

Parents as advocates

Whilst there are many forms of advocacy worthy of discourse in relation to disability advocacy and advocacy rights, the focus of this thesis is on Independent Advocacy. Nevertheless, it is important to acknowledge that parents have a role and responsibility to advocate for their child's rights to be realised in historical understandings of 'parenting', and this understanding is recognised in UNCRC Article 5. There is much evidence and research surrounding parents acting as advocates for the rights of their disabled child in the UK and elsewhere (Burke et al, 2019; Adams et al, 2017; Longfield, 2017; Wynd, 2015; Mitchell, 2012; Brady, 2011; McGrath, 2010;). Indeed, advocacy is more often provided by the parents of disabled child than independent advocacy (Brady, 2011; McGrath, 2010; Townsley, 2009; Elsley, 2010). Under the Care Act (2014), parents are recognised as natural advocates for their children (of any age), and Mitchell (2012) found that disabled young people may want the support of their parents in decision-making.

Whilst there are many disabled children in care for whom biological parents do *not* have continued parental responsibility, many children and young people in the residential care system are accommodated under section 20 of the Children Act 1989 and parents *still have parental responsibility* and can have an active role in their care, including an advocacy role. Under the Care Act 2014, a young person could choose not to be advocated for by their parent, and indeed a parent

could be unwilling or be deemed as “inappropriate” to advocate for their near adult/adult child by professionals. In addition, for some decisions made under the Mental Capacity act, the role of an Independent Mental Capacity Advocate (IMCA) is a right in itself. This in itself can be difficult for parents to accept.

Whilst this is important to acknowledge, parents as advocates are not the focus of this research. Yet often in advocacy practice, independent advocates are encouraged to seek, and are often reliant upon, parents and or carers for information about a child or young person's communication, and its meaning (Smith & Brackley, 2017), and therefore advocates often work alongside parents. There are issues with parents acting as advocates particularly, as findings by Elsey (2010) and Knight & Oliver (2007) suggest, that parents find it difficult to separate their own wishes and feelings from that of their child; sometimes it may be difficult to allow independent advocates to work with their children. This will be explored further within the context of my fieldwork research.

Statutory advocacy

The provision of, and a right to access independent advocacy, is defined now in legislation within the UK for adults and children under certain circumstances (Care Act 2014 (England), Children's Act 1989, Mental Capacity Act 2005 (England and Wales), Mental Health Act 1983, 2007, Mental Health (Care and Treatment) (Scotland) Act, 2003). Advocates working under legislation are required to complete training specific to the Act they will be working under within a given timeframe. It is important to note that legislation between regions differs. For example, there is no statutory duty to provide advocacy under the Adults with Incapacity (Scotland) Act, 2000 or the Adult Support and Protection (Scotland) Act, 2007 (Stewart & Macintye, 2013). Consideration will focus on English provision from hereon in.

The role of the Independent Mental Health Advocate [IMHA] under the Mental Health Act 1983 offers advocacy support for both adults and children detained.

The role of an Independent Mental Capacity Advocate [IMCA] under the Mental Capacity Act 2006 (amendments), is for very specific issues where there is nobody able to represent the person, and the remit of the Mental Capacity Advocate is advocating for the person's "Best Interests". The Mental Capacity Act 2005 is only applied to people over the age of sixteen. In practice, an IMCA has limited time to prepare a report and spends very little time with that person, but rather reads care plans, or speaks to support workers, for example. There is a real overlap between the work of an IMCA and a Care Act Advocate, however, the Care Act Advocate does not necessarily look towards a person's best interest but what that person wishes and wants, and tries to ensure that persons participation in the decision-making (Care Act 2014, Part 1.1 & 67).

The Care Act 2014 in England does oblige local authorities to refer to independent advocacy if there is no one suitable advocate and the person has substantial difficulties in: understanding relevant information, retaining information, using or weighing information, communicating views, wishes and feelings. There appears to be an issue with both local authorities and advocacy agencies themselves understanding the remit of the Care Act. Consequently, referrals across the country are patchy and inconsistent (SCIE, 2017). Indeed, the terminology "substantial difficulties" as a qualifying factor has led in practice to inconsistent referrals and take up of advocacy despite its legislative power (Mercer, 2017).

3.5 "Independent" Advocacy for Children and Young People

Independent Advocacy simply means that the advocate is not employed by the local authority or the setting in which they advocate, although the advocacy service may be commissioned by a setting (residential) or by a local authority. However, there are advocates working within some local authorities through in-

house services, particularly for children (Elsley, 2010; Longfield, 2016). An independent advocate is trained and should be working towards a qualification (City & Guilds Level 2 minimum Qualification in Advocacy). References are frequently made to various Standards of Practice and/or Provision for advocacy in the discussion documents around standards and practice of Independent Advocacy (Longfield, 2016; Griesbach & Waterton, 2012; DCELL Wales, 2011; Brady, 2011; Elsley, 2010). But there is no official registration as an advocate such as there is for nursing or social work within the UK.

The value of independent advocacy appears to be endorsed by many studies; from the perspective of other professions (Thomas et al, 2016; NYAS, 2013; Morgan, 2008), and of children and young people themselves (Pona & Hounsell, 2012; Knight & Oliver, 2007). However, Thomas et al (2016) echo the concerns raised by Brady (2011) and Wood & Selwyn (2013) that evidence regarding advocacy is largely anecdotal. Moreover, the evidence of advocacy specifically for disabled children and young people is limited (Brady, 2011; Franklin & Knight, 2011; Longfield, 2016).

Returning to the origins of advocacy it should be acknowledged that social care advocacy has strong links with legal and other forms of advocacy as far as the concept of standing with and for another and for the advocated to have a voice and right to argue a case or put one's views. Social care advocacy moved away from *representing* to *empowering and supporting* as the philosophical shifts in the understanding of vulnerabilities and rights, social justice and empowerment influenced advocacy practice. Critics of the term 'non-instructed' advocacy state that advocacy is facilitating a person's own voice, and therefore if a person is not able to communicate or instruct, the advocate cannot advocate. However, non-instructed advocacy could be considered to fall within the realms of advocacy if considering advocacy in its wider socio-historical terms, as representational advocacy to uphold rights and social justice. Nevertheless, there remains the

question as to the extent to which a person is facilitated to contribute or “instruct”, and the role of the advocate’s ability to receive the “instruction”.

In the absence of instruction, the advocate has to report on or base observations on a framework as such. In the UK, there are four models of non-instructed advocacy working recognised in practice within both adult and children’s practice namely, Witness-Observer, Watching Brief, Human Rights and Person-Centred models (Wilks 2012, Henderson n.d. and Coram, n.d.). The Witness-observer approach reports to others the advocate’s observations of the person’s life, including where their well-being is threatened. The Human Right’s based advocate will frame their observations and challenge practice using legislation and ‘Human Rights’ conventions. The person-centred model considers the person central and aims to develop a relationship with the person to inform their reporting to others ‘as-if-they-were-the-person’. The ‘Watching Brief’ developed by Asist (Assist Advocacy services, n.d.) is widely cited as a model of ‘non-instructed advocacy’ (Thomas et al, 2016; NDTi, 2016). It considers a number of factors within a person’s life to report and consider such as the ‘development and use of skills’, ‘community presence’ and ‘well-being’ (See Appendix 8).

There is a fifth model, the Best Interest Model whereby the advocate considers what would be in a person’s ‘Best Interest’. However, the use of the Best Interest model is not without its controversy (Boylan & Dalrymple, 2009) because it diverges from the aims of independent advocacy to advocate for a person’s feelings and wishes, not for what may be the person’s ‘best interest’ in the advocate’s opinion. This is often the defining factor between advocacy and other professionals such as social workers and nurses. It is nevertheless relevant in some advocacy situations such as working as an IMCA, as outlined previously.

The four models (not including Best Interest) hold the individual preferences and their rights central, with different emphasis in terms of what an advocate is looking for, and reports upon; for example, applying the rights based model, an

advocate may focus the right of person to partake in an activity through applying relevant legislation, whilst an advocate using a strictly person-centred approach may emphasise the person's observed dislike/ like of an activity. Literature in general from advocacy agencies in the UK suggests advocates for adults and children use a combination of models. In practice, the Watching Brief (See Appendix 8) and other approaches of 'non-instructed' advocacy are primarily *protection* and *provision* focused. Whilst it is important to consider the UNCRC in its entirety (Lundy, 2012), *participation* and "respect for their view of" children and young people with complex communication needs is crucial to this thesis. Facilitating a child or young person with complex communication needs to contribute and participate in decisions about their lives is particularly challenging for advocacy practice, whether this be deemed 'instructed' or 'non-instructed'. The Watching Brief is widely cited by children's Independent Advocacy agencies (Coram, Barnadoes, NYAS) but was not developed by children or young people's advocacy practitioners and there appears to be no evidence of academic study or critical examination of this particular model.

The challenge of this thesis is to examine the practice of advocacy and 'non-instructed' for children and young people with complex communication needs. It is particularly pertinent considering increasing demand, changing legislation, yet a lack of evidence to justify advocacy in upholding the rights of a child or young person. The Children's Commissioners have raised concerns regarding the lack of legislation concerning access to advocacy and advocacy provision in England, Scotland and Wales. However, the lack of data around outcomes to demonstrate its worthiness could diminish the argument for access and provision of advocacy for children and young people with complex communication needs. It maybe that 'non-instructed advocacy' is in a Catch-22 situation. The lack of non-instructed advocacy evidence is impacting on the awareness of non-instructed advocacy and therefore the legislation and provision. If non-instructed advocacy was more visible, and the needs of children

and young people with complex communication needs were visible, voiced and validated, it may have greater impact on services and future advocacy provision.

3.6 Advocacy and social work theory

The provision, practice, purpose and historical development of advocacy has been discussed. Advocacy theory will now be outlined and a theoretical framework for considering advocacy for disabled children and young people with complex communication needs will then be discussed in 3.7. My understanding of advocacy is rooted in my training and experience in social work, and indeed, there is much overlap in approach and practice. For example, empowerment is a key element of advocacy practice, alongside anti-oppressive practice and person-centred practice. Boylan & Dalrymple (2009, 2013), Wilks (2012), Thompson (2010), Brandon and Brandon (2001) all consider advocacy within social work practice and offer useful insight as to the basis of advocacy working in social work, as does Bateman (2000) within the nursing field. Bateman's principles of advocacy (2000), are based on professionals advocating on behalf of their clients/service users. Wilks (2012) links 'empowerment' and advocacy practice to develop a 'process model' of advocacy, built on mutuality and partnership working.

The first definitive textbook regarding *independent advocacy* in the context of social care within the UK was penned by Henderson and Pochin in 2001. They indicate that the lack of academic research around advocacy could be because of its roots in Citizen Advocacy, and the argument that its practice is intensely a personal interaction. Their work was largely based on their practice as advocates and managers of independent advocacy services. Much has developed since this well cited text, including the inclusion of independent advocacy within legislation (Mental Capacity Act 2005, Care Act 2014 in England, Children Act 1989). The

purposes of advocacy as defined by Henderson and Pochin (2001) have formed and still forms the basis of independent advocacy practice within the UK.

Payne (2002) and Dominelli (2002) identify three distinct theoretical perspectives that underlie social work practice. It is important to consider these because of the links between social work practice and advocacy. It is noted that advocacy in isolation has not been considered in terms of these approaches but has been implied in relation to advocacy in social work by Wilks (2013).

Firstly, the individualist reformist approach (Payne, 2002) or maintenance social work (Dominelli, 2002). This is often seen as traditional social work practice in that it seeks to address issues *of* the client, *for* the client and works within structures established within society. Secondly, the reflexive-therapeutic (Payne, 2002) or therapeutic (Dominelli, 2002) approach in which social work employs techniques such as counselling, psychosocial and non-directive approaches to enable clients to understand their own limitations and work out for themselves the means to address them or come to terms with their limitations. The third perspective is the emancipatory (Dominelli 2002) or social collectivist approach (Payne 2002). This sees social work as a vehicle for social change to address the inequalities and oppressions of society, which are the causes of the issues for the client, through anti-oppressive practice, feminist and radical social work.

The diversity of advocacy practice and its history can be seen to link with these three individual theoretical perspectives. For example, current individual casework in advocacy practice approaches the issue for which the referral has been made and addresses it within the existing social care system (maintenance approach). The relationship and mutual working of advocacy could be considered therapeutic, particularly if the individual moves towards self-advocacy. Examples of advocacy as a therapeutic tool can be seen in working with parents with learning disabilities (English, 2010; Gould & Dodd, 2014 and Tarleton, 2008).

One of the challenges of non-instructed advocacy is communication. Working in a reflexive-therapeutic way is often not the most obvious approach to 'non-instructed' advocacy by an advocate. However, this and the socialist-collective approach to an issue may be appropriate for non-instructed advocacy, if the person is deemed a non-instructed case because of communication difficulties but is still able to articulate their feelings and wishes in some way. Emancipatory practice in advocacy is a worthy aim, but people with complex needs may be relying on a third party such as a parent or carer to challenge the system on their behalf, rather than then themselves through an advocate.

The emancipatory approach to social work can be seen in advocacy practice in the past, and evidence by the IFSW (International Federation of Social Workers) in current advocacy by social workers world-wide. Advocates working in UK with individuals are often faced with the same issue facing client after client, such as access to speech therapy, or the reduction in support hours for clients with learning disabilities. The understanding that advocacy can work to address societal change is a challenge to advocacy practice within the UK with barriers to coordinating collectively to advocate for wider societal change. The recent NDTI recommendations and framework for advocacy outcomes for adults (NDTi 2016) calls upon agencies to look at the wider picture to influence or advocate beyond individual cases. This recent document is attempting to formalize and structure advocacy working, but also give purpose beyond advocating for the individual and highlights the importance of advocacy outcomes in relation to communities, social care, and the wider community as well as individual; in effect a move towards socio-collectivism.

The three perspectives help to understand the different means and approaches of advocacy practice both current and historical within the UK and abroad. The practice of advocacy can also be seen in the context of society's view of disability and disablement as previously discussed when considering the medical and social model of disability, and of society's views of children as participants in

decision-making about their own lives. Attention will now turn to the systems theory which will be used as a theoretical framework for examining the advocacy relationship within the context of the children and young people's lives and the society in which they live.

3.7 Systems theory as a theoretical framework

Advocacy practice, particularly where a person has complex communication needs, involves working alongside and interacting with other people around the person, and also in the context of the community, culture and political resourcing. The consideration of factors around the child or young person impacting on disabled children's rights, has been explored by other researchers, particularly in relation to family (Davey, Imms & Fossey, 2015; Saaltink et al, 2012; Baker & Donnelly, 2001; Dowling & Dolan, 2001), the school/education setting and the culture of the child or young person (Cohen, 2013; Fazil et al 2004). Advocacy with disabled children and young people with complex communication needs, has not been examined in terms of the advocate-child or young person relationship, alongside the relationship with the family and wider context of the child or young person's life.

I consider systems theory to be an appropriate theoretical framework to examine the practice of advocacy with children and young people. Bronfenbrenner's ecological 'systems theory' model (Bronfenbrenner 1979), conceives a child or young person and the people and context of their environment as being influential upon, and influenced by, the other. Systems theory identifies different levels of relationship within the eco-system surrounding an individual. In applying systems theory to advocacy, the levels of the ecosystem are described as thus:

- **The micro-level;** the relationship a child or young person has directly with parents, teacher, carer, health professional and importantly for this research, their advocate.
- **The meso-level;** the interaction and relationship the people of the micro-level have with each other around the child or young person. In the context of this research, the advocate relationship with parents, school and carers or health professionals who work with the child or young person.
- **The Exo-level;** the school, community, health services and the advocacy agencies.
- **Macro-level;** the political, cultural and legal systems.
- **Chrono-level;** the context over time which can change and develop.

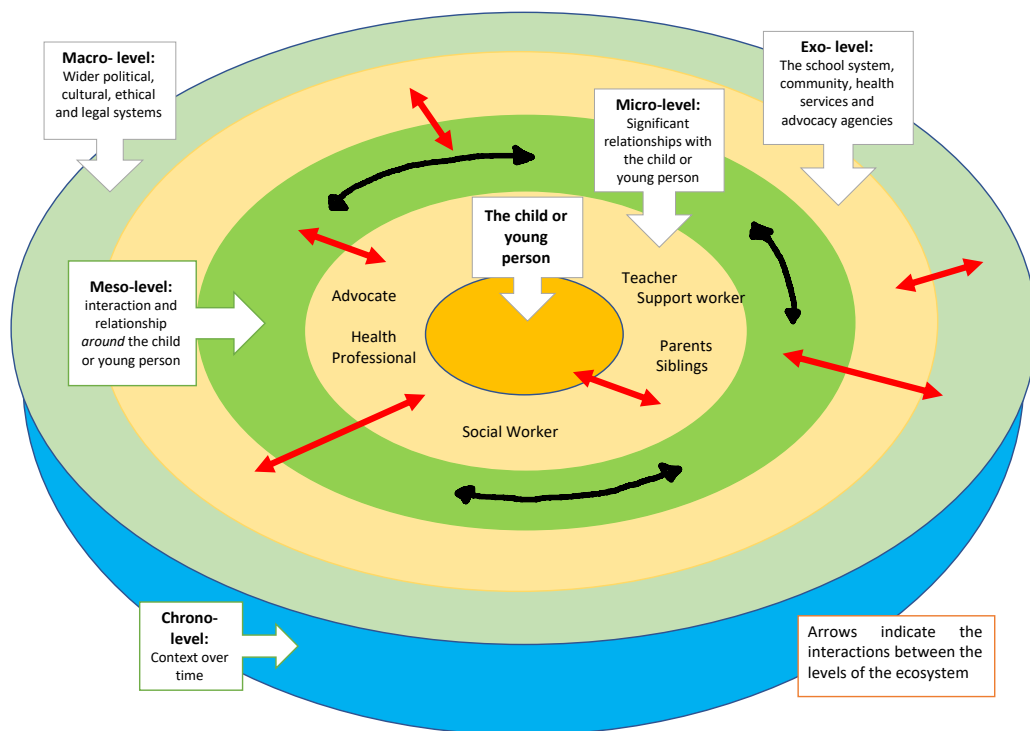


Figure 5: Diagram of Systems Theory after Bronfenbrenner (1979)

Systems theory keeps the individual as the focus, but also allows the context of the child or young person to be explored. Systems theory also recognises that the ecosystem is influenced by the central child or young person; the child or young person has 'agency'.

Advocacy practice can be considered to relate to the micro, meso, exo and macrosystems surrounding the individual at the present time, and the chronosystem of life events relating to that person, or indeed the history of advocacy and disability. A person lives within, is affected by and affects his or her family, the resources and attitudes of the wider community which in turn is affected by the social, political and economic climate. Therefore, an advocate needs to be aware of the systems *surrounding* the individual, but also the lines of communication *between* systems. The advocate can work anywhere within the system.

The beauty of applying systems theory is that advocacy remains person-centred with individual people remaining at the core. To return to advocacy practice and principles, systems theory could also be applied to other forms of advocacy. For example, self-advocating is also possible because of the support, perhaps on the mesosystem or indeed due to past support – (chronosystem). The advocate can advocate both for the individual within the micro system, but outwards towards the macro system. In effect, advocate for both *cause* and *case*. The advocate needs to understand the dimensions of the macro-level and the chrono-level and the interactions between the systems in order to avoid complicity and to be able to analyse and challenge rights violations.

Systems theory can be applied similarly to 'non-instructed' advocacy. In practice an advocate, in addition to developing a relationship and communication with an individual, will consult the people around the person, and look for previous expressions of wishes and feelings. This is a particularly useful method for working in a 'non-instructed' way for people whose capacity has become

diminished as a result of accident or illness. One of the challenges of working in a 'non-instructed' way with disabled children and young people with complex communication needs, is that they may never have been able to express their own wishes and feelings in the past, and their rights to wishes is sometimes challenged by parents. Another is the extent to which an advocate is able to distance themselves from the meso-system and the macro-system in order to challenge practice on behalf of the person.

Within my fieldwork systems theory provides a theoretical framework to explore and understand the impact and scope of the advocate within and to, the ecosystem of the child or young person the advocate is working with.

Concluding comments

In this chapter, I have considered the definition, development and practice and purpose of advocacy in the UK. How advocacy has been always part of social work practice but has now become distinct from social work as 'independent advocacy'. It is acknowledged that advocacy is part of other professional practice, and indeed parents often advocate for their child. Nevertheless, there is now a place for advocacy within legislation, including independent advocacy for children and young people under certain circumstances.

Of particular note within this chapter has been the concept of a 'continuum' of advocacy, in terms of both purpose and practice. The difficulties of definition have been touched upon, particularly with regard to the term 'non-instructed' advocacy. This will be returned to when discussing the findings of my research.

Advocacy has been part of social work practice and social work theoretical perspectives and concepts were discussed. Systems theory was explained to be an appropriate theoretical framework on which to base my research and findings

around advocacy for children and young people with complex communication needs.

Advocacy as a tool for supporting participation, and to uphold rights, has been discussed, and is evidenced in research and grey material. Yet very little has been researched about the advocacy relationship and the process involved, particularly for disabled children and young people. The aims of my research are to gain a deeper understanding of the use of advocacy as a mechanism for ensuring that the views of disabled children and young people are central to decision-making about their lives, and to understand and examine the practice of what is commonly termed “non-instructed “ advocacy for children and young people. The objective is also to develop a conceptual framework to enhance the understanding of advocacy for young people and young people disabled by communication needs, in order to better future effective advocacy practice.

In the following chapter, the methodology for carrying out my research is discussed in depth.

Chapter Four:

Methodology

The aims of this research have been to gain a deeper understanding of the use advocacy and 'non-instructed' advocacy through examining the evidence for, and the practice of, advocacy with disabled children and young people with complex communication needs. This chapter is a justification for the methodology and approach adopted. It is a discourse on the research journey; from planning and adapting and carrying out to analysis of data.

Before discussing the methodologies utilised, I will outline my approach to the research in 4.1. I will then take the three methods of data collection used and detail the rationale for that particular methodology and how the data was gathered. Each section will end with a brief narrative of the data collected:

- 4.2 review of literature evidencing advocacy for disabled children and young people in the UK
- 4.3 ethnographical methodology to study the child or young person relationship with their advocate in advocacy practice
- 4.4 semi-structured interviews with advocates using vignettes

The chosen method for the analysis of the data is considered in 4.5. I then outline the limitations of the methods I used and conclude with a summary of the research journey.

4.1 Research Paradigm

The practical considerations and methodology form a significant part of this chapter. However, before considering my research methodology to fulfil the aims and objectives identified, consideration must first be given to my chosen research paradigm. Guba (1990) considers three elements of the research paradigm; *ontology*, *epistemology* and *methodology*. Bryman (2012) also identifies *values* and *practical considerations* that influence social research.

Ontology, epistemology and values underpin and influence the methodologies chosen and these will now be considered before outlining my rationale for the methodologies adopted.

Ontology

Ontology is in essence questioning *what* is reality; is reality a fact; objective, or subject to interpretation; subjective or interpretative (Bryman, 2012)? The concepts of advocacy and of authentic voice are pertinent to consider.

I do not consider concepts and the practice of advocacy to be void of interpretation or completely objective. Advocacy has been discussed as a means for supporting a person (or group of people) to understand their rights and choices and to remain at the centre of decision-making through their active participation and voice (chapter one). Whilst rights could be described as ‘facts’ under law (e.g. Care Act 2014) or conventions (UNCRC, UNRPD), the experience and practical workings of advocacy are not universal as demonstrated in earlier chapters. There is fluidity in an advocate's role from standing behind the person-to enable self-advocating, standing with the person or standing for the person to represent their views. In short, advocacy is based on relationship and communication to find meaning and ‘reality’ of voice for that person, and to further communicate this to others.

The term 'voice' is contested and subject to historical and socio-cultural interpretation (Tidall, 2012). I have defined 'voice' as the expression of the child or young person's lived experience in which their wishes and feelings may be conveyed. Whilst this enables the broadening of the understanding of 'voice' to include the non-verbal expression, the reality of hearing the *authentic voice* of children and young people cannot be assumed to be a fact (Clark & Richard, 2017). If children and young people are recognised as having agency, they may choose *not* to engage (Lewis, 2010). The hearing of the authentic voice is also impacted by the researcher's own agenda, the power dynamics of adult and child relationship and the accommodation of diverse communication forms by the hearer of 'voice' (Stafford, 2017; Clark & Richards, 2017). Thus, I consider the 'voices' of the children and young people my study as my *representation* of their voice (L'Anson 2013), as a researcher and advocate at that time and context rather than absolute 'fact'.

How 'voice' is understood through the tool of advocacy is subject to interpretation. Therefore, I approach this research as an 'interpretivist' to discover *what is* advocacy and voice for both the advocated for and the advocate. I will also consider the terms advocacy and 'non-instructed advocacy' in light of legislation and policy.

Epistemology

Epistemology is the questioning of *how* we consider reality. Whilst there are different perspectives (Patel, 2015), I take a constructivist/interpretivist and critical view, in that whilst reality needs to be interpretative, advocacy, particularly for disabled children and young people has to be seen within the context of socially- constructed views on 'voice', agency, rights and disability.

As discussed in Chapters One and Two, evidence from research suggests that rights of participation are not realised equally for disabled children and young people, particularly with complex communication needs. Participation and voice are subject to the recognition of voice and agency by others as a child (Holland et al, 2019), and also as a *disabled* child or young person (Wickenden, 2019; Liddiard et al, 2019; Greathead et al, 2016; McNeily, McDonald & Kelly, 2015; Nind, Flewitt & Payler, 2010). However, as Goodley and Runswick-Cole (2012) point out in their analysis of discourses around disabled childhoods, there is a danger of ‘othering’ disabled children and young people. I consider that all children are unique, with differing abilities, likes, dislikes and lived experiences. Their voices are therefore unique but equally valid as an expression of their humanity. Whilst some voices are more challenging to hear and understand, it is beholden to the listener to recognise their own role- whether through time, skill and experience to overcome those challenges. The reality of rights, particularly of voice, is subject to the recognition by the ecosystem around them. Hence my approach to examine the micro-level of the advocacy relationship between the advocate (as a tool to support participation) and the child or young person within the context of the ecosystem.

There is quantitative evidence of the existence of ‘non-instructed advocacy’ for disabled children and young people with complex communication needs in the UK (Longfield, 2019). However, the quality of advocacy and how advocacy supports the voice of individual disabled children and young people within the advocacy relationship, has not been researched in depth. Examining this relationship and how this enables ‘voice’ in the context of the ecosystem of the child therefore is critical. It is also clear that ‘non-instructed’ advocacy for disabled children and young people requires further definition through critical examination of the understanding and meaning given to the term by referrers, carers and practitioners and how this form of advocacy is subsequently actioned.

It is therefore appropriate to use a qualitative methodology within the interpretive and critical research paradigm.

Values

Bryman (2012) emphasises that *values* influence elements of research, including the research subject itself. As outlined in the introduction, I am passionate about advocacy and rights, but I am also aware that without research to bring disabled children and young people's advocacy to the forefront, their rights to participation, provision and protection may further be eroded.

In Chapter Two, I proposed that a factor of 'value' be considered as an additional factor to Lundy's model of participation and the elements of expression, support and regard for 'voice' after demonstrating that the voice and agency of disabled children and young people was not equal that of their non-disabled peers. I stated that if we consider voice as the expression of a child or young person's lived experience in which their agentic wishes and feelings may be conveyed, not hearing those voices, risks not affording *value* to their lived lives and thereby de-humanises the child or young person. Therefore, to exclude the voices of the subject of my research would have been inconceivable. The value I place on the child or young person to be at the centre of the research greatly influenced my approach and my ideals for my initial research methodology and methods.

Approach

In order to understand advocacy, the micro-level of the advocacy relationship and the meso, exo and macro-levels in which advocacy is practised, need to be considered. Therefore, in considering the methodology for this research I wanted to capture both the 'bigger picture' of the evidence of current practice in the UK through a literature search, and the evidence of the advocate-child or young

person relationship through direct fieldwork with children and young people and their advocates.

Why direct research with children, young people and their advocates?

Researching anything will inevitably involve the subject of the research itself. In other words, meaningful research cannot take place without the subject of the research being part of the research in some way. The difficulty with researching advocacy and ‘non-instructed’ advocacy for children and young people with complex communication needs is that the subjects of the research are a) children b) individuals with complex communication needs. The ethics of consent was a major consideration for my research because of the age of the participants, regardless of their communication needs. Yet children are able to be active participants in research where parental consent or consent of the person with parental responsibility, has been obtained (Head, 2011; Shaw, Brady & Davey, 2011). Nevertheless, careful deliberation must be given to both the precedent set and the appropriateness in terms of ethics and rights of people with complex communication needs to be involved in research where consent may be difficult to ascertain.

Observations of young people with complex needs in advocacy within wider studies of children's advocacy have been made (Oliver, 2003; Knight & Oliver, 2007), and research carried out with disabled children and young people with complex communication needs (Underwood et al, 2015; Wickenden, 2011). One of the barriers identified to involving disabled children and young people and particularly those with communication needs, has been the issue of “gatekeeping” and the assumption of professionals and parents that a child or young person would have nothing to contribute (Franklin & Knight, 2011; Mitchell & Sloper, 2011; Franklin & Sloper, 2009).

The Children's Commissioner report (Longfield, 2017) demonstrates clearly that the assumption of someone not being able to communicate verbally and therefore they have no meaningful contribution to make, can be challenged and past studies such as Underwood et al (2015), McNeilly et al (2015), Singal et al (2014), Wickenden (2011) support this. Indeed, participation in research is ethical, a right, and a matter of social justice (Bryne & Kelly, 2015; Mitchell et al, 2009; Cousins & Milner, 2007; Kelly, 2007). Although there are potentially barriers from social constructs and views of disability (Curran & Runswick-Cole, 2014; Davis, Watson & Gallagher, 2009; Connors & Stalker, 2007).

The premise of this research is that the child or young person in the advocacy relationship should remain central to the research. From the outset, participation through observation of the advocacy interaction was my intention. However, in order to fulfil the aims of the research to develop a conceptual framework of advocacy for children and young people with complex communication needs, studying the relationship of the advocate to the young person was also important to consider. Challenging other professions' practice and supporting clients to understand their rights and choices appears to be a feature of advocacy (Bauer et al, 2013; Macintyre and Stewart, 2011; Tarlton, 2008). A question for fieldwork is the process by which advocates negotiate boundaries and rights, and indeed how they themselves gain the knowledge and understanding of rights and legislation.

Use of secondary data has been used to research children's advocacy provision through analysis of data supplied by advocacy agencies (Children's commissioners and Thomas et al, 2016). However, as stated previously, my aim is to understand the advocacy relationship *itself*. Whilst analysis of case notes and minutes of meetings may be useful in triangulation and was my intention to carry out as part of my chosen methodology, secondary data *alone* would not provide the nuanced detail of the advocacy relationship, nor the concepts of and approach to advocacy by advocates themselves.

A mixed methodology

I used the theoretical framework of systems theory to examine the rights of participation within the ecosystem of disabled children and young people with complex communication needs in the UK. I consider that, in order to understand advocacy, the micro-level of the advocacy relationship *and* the meso, exo and macro-levels in which advocacy is practised, need to be considered. Therefore, in considering the methodology for this research I wanted to capture both the 'bigger picture' of the evidence of current practice in the UK through a literature search, as well as the evidence of the advocate-child or young person relationship through direct fieldwork with children and young people and their advocates.

This three-pronged approach I believed was more likely to achieve a robust understanding of advocacy on which to build a conceptual framework for future advocacy practice.

Figure 6 illustrates how the evidence was gathered through three methods.

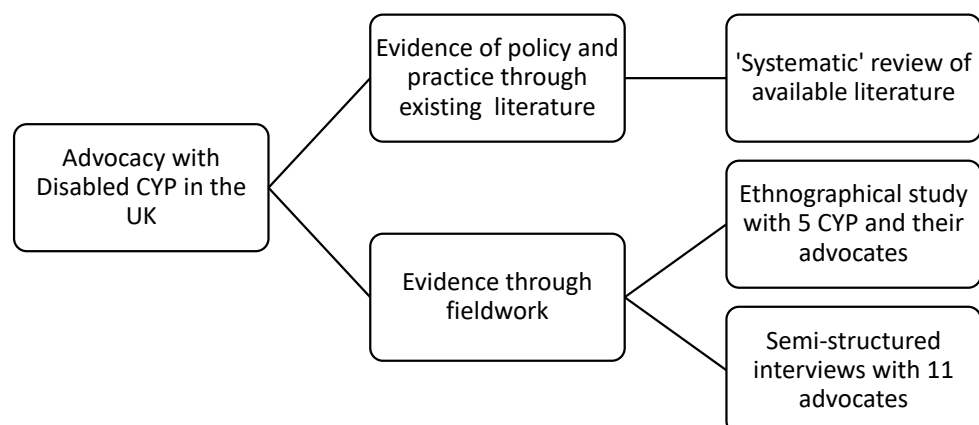


Figure 6: Evidence gathered through methodological approaches

I will now take each method of data collection and discuss before outlining how I analysed the data gathered from the three methods.

4.2 Literature Review

The purpose of the literature review was to explore what is already documented about advocacy and 'non-instructed' advocacy for disabled children and young people with complex communication needs within the UK. I start by outlining the rationale of my approach before detailing the search terms and adaptations made in the gathering process. I conclude with a narrative of the data collected as this is significant to the overall findings of the research.

Rationale

To capture all the available academic and grey literature, a systematic search was utilized using academic search engines. Whilst the manner of data collection is described as "systematic" in order to encompass relevant studies for accurate analysis and discussion of the current advocacy situation in the UK, the review of the literature itself was narrative. This was necessary as my overriding research aim is towards a conceptual framework, in other words a theory induced from the findings of my research (Bryman, 2012). Grey literature was included as it was quickly discovered that much of the evidence for advocacy with disabled children and young people was as a result of reports by advocacy agencies and children's commissioners rather than academic sources. Whilst there are a number of academic articles around disabled children and young people's participation highly relevant to this research, I was clear from the outset that this particular search needed to only capture documents that acknowledged advocacy specifically in some way as the role of advocacy was the focus of the research.

Search terms

The purpose of this literature review was to firstly explore what is documented about advocacy for disabled children and young people with complex communication needs, and from the documentation, seek to conceptualize current understanding and use of “non-instructed” advocacy. Therefore, the following terms were appropriate to commence the search in Keyword, Title and Abstract:

advocacy OR advocate (advocacy action by advocate)

child OR children OR adolescent OR youth OR young people (to capture wide terminology)

disability OR disabled

non-instructed OR non-directed (non-directed Advocacy is a term observed in prior reading to describe non-instructed (see Oliver & Knight, 2007).

It became obvious early on in my searches that the search terms were too narrow and it became necessary to re-examine my search terms. To discover where the issue might be, terms were excluded in isolation. It became apparent that there was evidence of non-instructed advocacy when the terms:

child OR children OR adolescent OR youth OR young people

were removed. However, the resulting documents were largely tender documents or research with older adults and related to non-instructed advocacy by Independent Mental Capacity Advocates [IMCA's].

Removing the terms *non-instructed OR non-directed*, also proved that there was documentation around advocacy with disabled children and young people. At this stage, having an awareness of literature related to advocacy with disabled children through my wider reading, I began to question the notion and concept of “non-instructed” advocacy as a term. This will be explored later. I re-examined my focus for the research and concluded that what is termed “non-instructed”,

describes advocacy with, and for, children with communication needs. Therefore, further searches were re- conducted using the following:

New search terms:

TITLE-ABS-KEY (**advocacy** OR **advocate**)

AND TITLE-ABS-KEY (**child** OR **youth** OR **young person**)

AND TITLE-ABS-KEY (**disability** OR **disabled**)

[AND TITLE-ABS-KEY (communication)]

I then eliminated literature reviews and documents related specifically to other countries other than the UK. During my reading of the body of the texts, it was clear that both the understanding of the term advocacy and advocacy practice in other countries was strikingly different to that of the UK. Whilst it is important to acknowledge the contribution of this research to the wider issue of advocacy working practice and international conceptualization of advocacy with young people and children, the other elements of my research (ethnographic study and interviews with advocates) concern advocacy practice specifically in the UK and under legislation in England and Wales. My research on advocacy is focussed within the UK in order to be able to inform policy and practice within the UK.

A number of additional articles were found through “snowballing” using the references from documents read and conducting on-line search for the original material. It became apparent that my initial method of using academic search engines was not drawing documents found in the references of articles read. In addition, I was aware of recent relevant reports by Children’s Commissioners that had not been found but that would be advantageous to include. A further search was therefore conducted using the general search engines *Google* and *Bing* using the terms:

advocacy OR advocate

child OR children OR adolescent OR youth OR young people

disability OR disabled

Websites of advocacy agencies and children's commissioners were also searched. Further 'grey' material including government, charity and advocacy agency reports were found. Many were not specific to addressing advocacy with disabled young people, however, if they addressed "advocacy" and "Disabled or disability" they were included in the documents to be considered for inclusion.

I continued to read and examine the material until it became apparent that I had gathered all the material that was:

- a) Currently available (some appeared to be paper evidence that was no longer available).
- b) Relevant in that it addressed Advocacy, Children and young people, AND either disability or communication needs.
- c) Was research conducted in the UK or addressing advocacy in the UK.

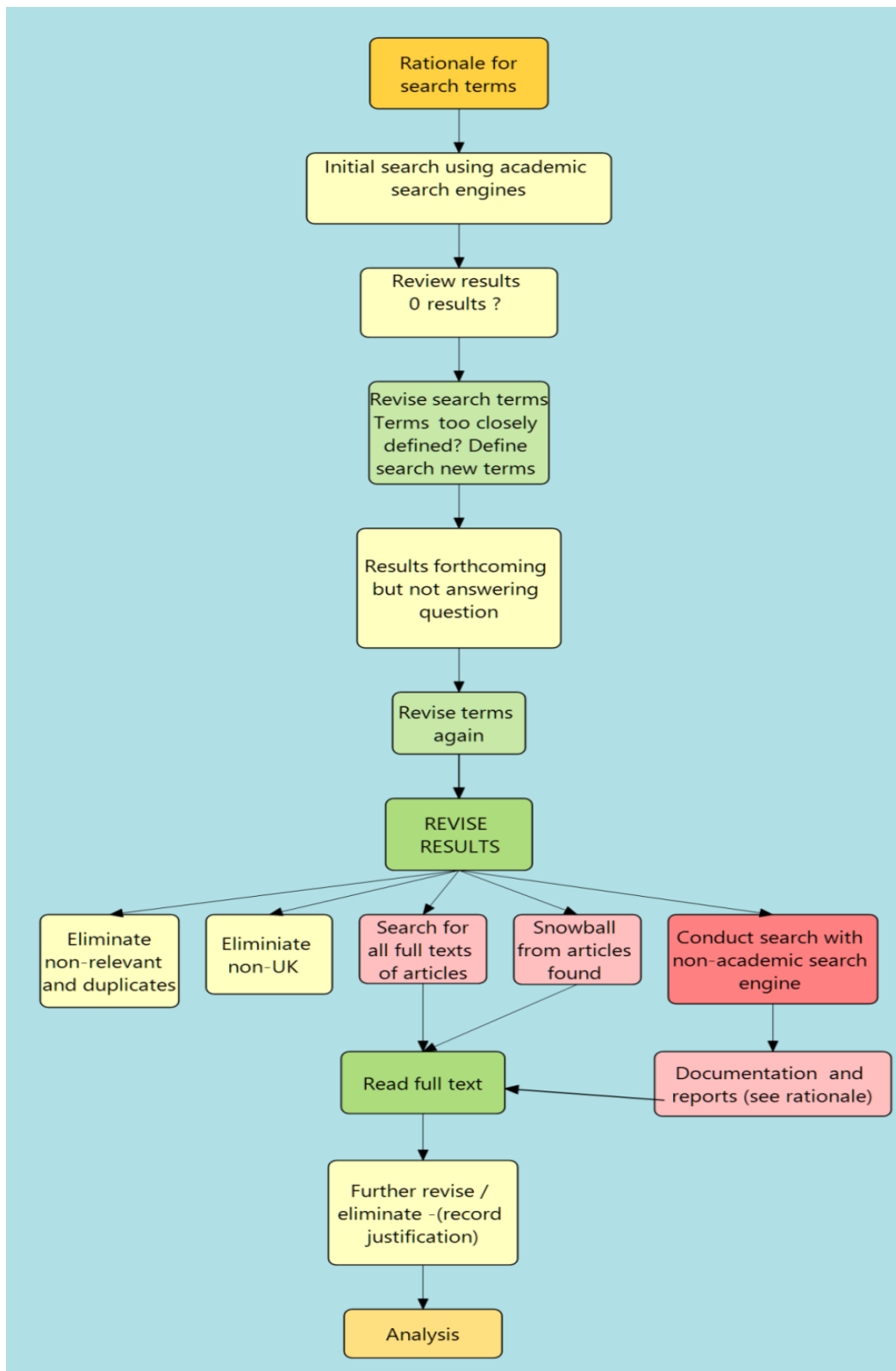


Figure 7: Flow chart of the literature gathering process

Narrative of data collected

The final number of documents collected was twenty-six in 2017 but this number increased to twenty-nine during the course of the literature review stage of my thesis as works were published or discovered to fit the criteria. I conducted an additional search following the criteria outlined and checked advocacy agency and Children's Commissioner's websites. In 2019, a further report was published by the Children's Commissioner for England and a relevant document published by the Care Quality Commissioner [CQC] and by Walters (2019) regarding Medway serious care review. These have been incorporated into the final findings and discussion found in chapter five.

4.3. Ethnographical study of children or young people and their advocates

An ethnographical study of children and young people and their advocate within the context of advocacy practice was initially the only fieldwork methodology intended. It gained ethical approval (see Appendix 1) after firstly approaching the Children's Advocacy Consortium, and then further discussions with two advocacy agencies. Full ethical approval was granted by Coventry University following a rigorous approval process. The ethical approval was ratified and adopted by University of Portsmouth post fieldwork (after transfer) in regard to data storage.

Rationale

Ethnography enables a prolonged observation of interaction and ethnographical studies have been used in gathering qualitative data in the social science field for many years (Bryman, 2012; Coffey, 1999; LeRiche & Tanner, 1998; DeMontigny,

1995). Ethnographical research has been used in health and social work settings and with vulnerable groups such as bereaved children (Coles, 2015; Fergerson, 2014; Recoche, OConnor, & Clerehan, 2012; Tyson, Greenhalgh, Long & Flynn, 2009; Cooper, Lewis & Urquhart, 2004). Many researchers have identified that ethnographical studies, particularly involving non-participatory observation can prove insightful into actual practices of their subjects that would not otherwise have been identified through interviews. For example, Ferguson (2014) was able to uncover details of practice, such as the social worker skills in interacting with children and young people. Carlile (2012) also found issues such as attitudes of racism emerged through ethnographical research.

Ethnographical studies have also been used and critiqued with children and young people with complex communication needs (Wickenden, 2011). For these reasons, data gathering through being a 'non-participatory observer' (Robson, 2010; Bryman, 2012), was felt to be highly relevant and most suitable to maintain the participating children and young people at the centre of my research, but have as little an impact on the advocacy process itself. The intention was to become "immersed" in the advocacy agency over a period of time, thus gaining insight into the subtleties of the practice of advocacy and "non- instructed" advocacy for disabled children and young people with complex communication needs. This method of data collection sits well in the parameters of the interpretive- critical research paradigm. I would be able to observe the advocacy process at various stages from referral to completion and triangulate own observations in advocacy with that of the advocates notes and discussions with advocates. It was hoped this would enable a realistic sense of advocacy on the ground practice and the interaction between advocate and the child or young person. The reality of the situation within the advocacy agencies meant that, ultimately, I was not able to become immersed in the advocacy agencies themselves as intended. Nevertheless, I was able to carry out 'non-participant' observations of advocacy visits in their entirety and speak before and after to advocates and others working with and around the child or young person.

Alternatives considered

Various alternative methods were considered for data collection for this study within the research paradigm identified. Questionnaires and interviews with people *around* the young person are valid means to capture the views regarding outcomes for that young person and have been carried out previously (Thomas et al, 2016). However, this method alone would not capture the interactions that take place between an advocate and a young person.

Interviews with the child or young person to determine their views regarding the advocacy that they have received may be a useful tool and indeed has been used widely in previous studies with children in general and disabled children, but not specifically for 'non-instructed' cases (Thomas et al, 2016; Knight & Oliver, 2007). This should not preclude children with complex communication needs (possibly necessitating non-instructed advocacy) from being part of research. As discussed previously, communication and participation in research is both possible and desirable for disabled children and young people with complex communication needs (Mitchell & Sloper, 2011; Simmons & Watson, 2015; Underwood et al, 2015). However, to gain evidence of the advocacy relationship and a child or young person's insight into the advocacy process, I would need to investigate the individual child or young person's communication methods through talking to those familiar with the child or young person, observe current communication to learn how to best communicate with that individual for myself. From my experience with adult advocacy, this is both time consuming and involves building up a relationship with that person. There is potentially a danger that the child or young person's relationship with me could invalidate my observation of communication used by the advocate and detract from their relationship. It must be remembered that for the child and young person their primary objective in using advocacy is a resolution of the issue for which advocacy has been sought or offered, not my research.

Video observation of interactions between advocate and the child or young person may address the above issues of communication and potentially distracting from the advocacy relationship. However, the use of eye movement or slight facial expression change that can be the only means of communication for people with complex communication needs could render videoing a very technical and exacting challenge. This was beyond my capabilities considering the time constraints to develop such skills, and therefore was rejected.

Challenges of this methodology anticipated and encountered

Negotiating access

The fact that I have advocacy experience I hoped would open doors, indeed Coles (2015) indicates that her recruitment was aided by the fact she was perceived as an 'insider'. I felt to some extent this was the case, particularly in talking to managers from the outset; for example, my understanding of the issues around terminology helped communication. Leigh (2014), Brewer & Sparkes (2011) and Coffey (1999) comment extensively on the issues of remaining objective when in familiar settings of their ethnographical research. Having experience as an adult advocate, and training and experience working with children and young people and indeed as a parent, I was familiar with advocacy and non-advocacy practice including transition planning for young adults aged seventeen to twenty-five and many issues facing children and young people. However, I did not have experience or qualifications specific to advocacy with children under eighteen. This position of both being *familiar yet strange* with advocacy practice in these settings, provided a platform for objective insight (Best 2014) and also meant that, whilst revealing my advocacy past and having that commonality with advocates, I also was able to re-assure advocates that they were experts in their field, and my role was to find out, not judge.

Researcher presence

It is acknowledged that that researcher's presence can be a factor in the acting out of roles assumed by the participants, that might not be acted out if the researcher was not there (Best, 2014; Robson, 2012). However, I hoped that maintaining a sense of *marginality* (Best, 2014) would be possible within the settings, by the appropriate use of "self" (Coffey, 1999) and presenting my research and self as non-judgemental and non-threatening. Having established clear boundaries and my position as researcher, I hoped that over the period of my observations, advocates, children and young people, and other "actors" within the setting would become used to my presence and feel confident to be themselves.

In reality, for one the CYP¹⁴, Rowan, my presence had an impact in that Rowan wanted to interact with me. To ignore 'Rowan's engagement with me, their 'voice' would have been completely inappropriate. I was entering their world and felt honoured that they accepted my presence and made requests of me (to go with them and the advocate to another room). One of the advocates admitted that they had felt rather nervous at the anticipation of me observing them, but they soon felt at ease. Two advocates spontaneously reported that they found it useful talking through visits with me as it made them reflect more on their practice. In effect reflection that the advocates may have not done otherwise could be seen as influencing their practice, but I am not sure how this could have been avoided in carrying out the ethnographical study.

Consent and assent

The settings, commissioners and advocacy agencies themselves were approached to grant permission for me to carry out the research. Parents and carers or "responsible persons" (DoH, 2008) acting for the child or young person

¹⁴ CYP abbreviation used so as not to identify whether individuals are 'child' under twelve, or 'young person' over twelve. This is necessary as the sample group was very small.

were also approached for consent for their child/ward to participate. However, if a young person is over sixteen and subject to the Mental Capacity Act 2005 for consenting to take part was an issue for consideration. Decisions made on behalf of someone for them to take part in research, is based on whether that their participation is in their 'best interests'. This issue was not raised by the children's advocacy agencies for their young people eighteen and over but was by the adult agency approached later on in the research project and highlights an issue for future consideration. It may offer some explanation as to why particularly non-instructed advocacy has not been widely researched previously.

It could be argued that research cannot demonstrate that something will be in their best interests other than they will be represented within the research itself rather than not considered at all. Wiles et al, (2007) Nind (2008), Simmons & Watson (2014), argue that the rights to participation need to be weighed up against the question of capacity to consent. This applies not to just children, but to people who are unable to give clear consent either by cognition or communication issues. It is a matter of irony that advocates themselves would be part of the process of informing the best interests meeting as to the potential wishes and feelings of that young person to be involved in the research project about advocacy.

The child or young person is a central premise of my research, therefore I carefully considered how I might obtain assent or consent from individuals directly early in the process of designing the research proposal. During the ethics application, I discussed with advocacy managers how this might be possible. As a researcher, and as an advocate I would seek to present information and be satisfied of consent/assent for myself. Given that the children and young people would need tailor-made forms of communication about the research and I did not yet know the children or young people, it was agreed to ask advocates and/or parents to explain the research and my presence as they were the experienced in the individual's communication and understanding. This is consistent with

other research with disabled children and young people with communication needs, who may not be able to articulate (Simmons & Watson, 2014; Underwood et al, 2014; Wickenden, 2011). This was approved by ethics and made clear to the settings and local authorities (See Appendix 2i).

I witnessed that three of the CYP of the study were given an explanation by their advocate at the start of my first visit. One advocate referred to their previous conversation with the CYP about bringing someone with them on their next visit, demonstrating they had indeed taken time to explain. I am aware that two of the CYP parents had spoken to their child prior to my first observation. It was clear that three of the settings had spoken to the CYP before my visit, however the extent or depth of the explanation was not stated. In two settings I was also introduced by staff members to other CYP or service users as I passed through shared spaces. Although this was not intended for the purpose of seeking explicit consent, I was mindful that I was entering a shared space of other CYP as well as the CYP I was observing with their advocate and felt this was positive practice by the settings.

I was very mindful of the rights of the child or young person to assent or withdraw assent to my presence at any time during the observations, even if consent was given on their behalf by others. Agreement was made with advocacy agencies and written into the ethics proposal that assent would be sought, and my presence would be at the discretion of advocates and staff who knew the child or young person and their particular communication methods during each visit. This was also made clear to parents and carers, and advocates discussed with me at the start of the first, and subsequent visits. In reality, there was only one occasion where the decision was made for neither the advocate nor myself to visit one CYP due to their distress at the time. On another occasion I used my own discretion not to follow a CYP as they appeared to want to have their 'own space' and not be followed. My decision was later verified by staff to be the appropriate action.

Ethical considerations

Advocacy deals within sensitive areas of care. This research inevitably involved people's personal lives and those of their family yet should remain confidential. Sensitive issues have been researched before, for example Brewer and Sparkes (2011) ethnographical study with bereaved children and Cossar et al (2013) research with young people who had experienced abuse. Whilst it is important to record some detail to reflect the stories of the people involved, it is recognised that the numbers of children and young people with complex communication needs within the UK is relatively small. Care was taken to ensure that people could not be identified within the reporting of the research, for example generalizing issues in reporting rather than use specific medical diagnosis to avoid inadvertent identification.

Anonymity had been assured in ethics approval and participant information and this was continuously scrutinized throughout the write-up stage. I am aware that the participants, settings, advocacy agencies and parents, as well as the young people themselves, should be able to access the findings of my research. In the writing up of the research, the children and young people were given gender-neutral names and pro-nouns 'they' and 'their'. Sensitive issues were only described in general terms and the child or young person's pseudonym not used.

Adaptivity

Because of the nature of an ethnographical study, flexibility was identified as a key in collecting rich and useful data. From the outset, I was aware I was not able to predict precisely how many cases I would be looking at, nor how many advocates, parents or professionals I may be able to question. My intention was to be reflexive in my approach, using my field notes and reflections, to inform the direction of my research. My plan was to observe advocacy in action in two advocacy agencies to enable a wider experience and contribute to making the findings more credible and transferable (Yardley's criteria, Yardley, 2000). I

understood from my own experience of working in different agencies with the same aim (i.e advocacy), that the interpretation of legislation, policy, working relationships with social work teams and within multi-disciplinary teams can vary between settings and was keen to capture this if possible.

One anticipated difficulty affecting validity from the outset was the small numbers of participants limited by the time available, geographical limitations, and the limitation and capacity of the advocacy agencies themselves. It was clear several months into the project that there was lack of cases due to Agency Two's difficulties, and despite contacting other agencies, including adult and in-house providers, issues of consent, current suitable cases and contract issues, meant that no additional cases were going to be forthcoming. Whilst later I was able to observe several cases through Agency Two, I needed to adapt my research and therefore gained ethical approval for interviews with advocates. This will be detailed in 4.4.

Data collection and recording methods

Attention will now turn to the considerations I made as to the methods of collection and recording of the data from my observations. Robson (2010) and Fry, Curtis, Considine & Shaban (2007) state the benefits of having a framework or protocol for clarity in observational studies. This is not to limit the potential of the observation of the material gathered but to ensure that important aspects are not overlooked or unreported. Yet it has to be flexible enough to capture the unexpected which may turn out to be pertinent in the final analysis.

Observational Framework Protocol

Several models of observation have been used by researchers (Siminoff & Step, 2011; Robson, 2010; Bryman, 2010; Tyson et al, 2009) and applied in different contexts. Frameworks divide observations into categories. A much-quoted

framework is that of Spradley (1980) who described nine dimensions of observation. Rothstein (2002) developed a framework with four A's; Atmosphere, Actors, Activities and Artefacts. However, because of the specific nature of advocacy and interactions between the advocate and the child or young person, these are not able to be replicated appropriately for this study. As detailed previously, advocates working with people with complex communication needs, often rely on the previous experiences and interpretations of others for information regarding communication tools and the meanings of gestures etc. Yet, as Simmons & Watson demonstrate, this can be challenged (2014). It is therefore also vital to record as clearly as possible how other people are interpreting the communication that is given by the focus participants, as well as recording as clearly as possible non-verbal communication observed.

Within the collection of data, there is factual observation; what is seen and heard and the sequence of events. There is also the aspect of collecting and recording the actor's interpretations of their actions and reactions to the factual and their approach, emotion and purpose to the observed interaction. Ferguson's research found (2014), much information and conversations about perceptions and details can be picked up in the informal environment of the car. I hoped that that it would be possible to glean information, thoughts and feelings of the advocates in this way.

My framework drew not only on direct observation of advocacy but on information gathered from other sources, such as the informal discussions with advocates or case notes, and the context of the visit (See Appendix 3i). I used my experience of advocacy, social theory and my understanding of existing frameworks to develop this specific framework. Whilst I hoped to *induce* a conceptual theory of advocacy from my research, I was aware that my approach was influenced from my background and literature reviewing and therefore was also *deduced*. This will further be discussed when considering data analysis.

- **The descriptive element** – the structure, time and events of the advocacy interaction including a record of the communication in all senses between the advocate and the child or young person whether that be behavioural, verbal, non-verbal gesture, facial or other.
- **The interpretive element** – the recording of the internal understanding of the interactions by parties, the approach of the advocate, the meaning given by the advocate and the plans and thinking of the advocate influencing their interventions. This also included the interpretation of the actions and interactions of the child or young person in field notes and reflections of the Observer.
- **The contextual element** – the context of the intervention in terms of history, other players, purpose and the method of advocacy approach adopted by the advocate and the impact of the advocacy interaction on the rights and voice of that child or young person.

For this research, data was recorded through the use of:

- Reflective field work notes.
- Observation framework (See Appendix 3i).
- Detailed observation sheet (See Appendix 3ii).

Gathered from:

- Observation of the advocacy interaction and the context.
- Informal conversations with advocates.
- Sighted notes and reports of advocates (with permissions).

Data generated

The initial fieldwork data consisted of:

- Records of seventeen observations of nine children or young people.
- Three in-depth step-by-step commentary on non-verbal communication.
- Five advocates were observed, four advocates were interviewed in depth after advocacy, two also partook in the interviews using the vignettes.
- Eleven reflections (note some were reflections on a single visit where more than one child was observed).
- Eight settings (three in same grounds and organisation).

One of the advocates was only observed for one visit for two individual CYP within the residential setting. The interactions were recorded, but the advocate did not wish to be interviewed or elaborate on their thoughts after the observation work. I felt that I could not use this data because of the narrowness of the data collected by virtue of the lack of input from the advocate themselves.

For an additional two young people in the residential/school setting, their visibility to myself and contact with the advocate at the time of visiting was extremely short because of the situation within the setting and for one visit only. I felt that it would be inappropriate to comment or draw any conclusions from observations of the interactions between advocates and child or young person because of the brevity of the single observation.

My criteria for inclusion in the final data to be analysed, was that the child or young person had to:

- have been visited on at least two occasions.
- and that the advocate was able to talk through with me the advocacy interaction in context for that child or young person.

The final data set consisted of:

- Records of thirteen visits (or observations) of five children or young people in eight settings (three in same grounds and organisation).
- In-depth interviews with four advocates after and/or during the duration of period of advocacy. (Two advocates also partook in the interviews using the vignettes).
- Reflections in addition to notes on observation framework, and three detailed observations of non-verbal communication interactions (it was not possible to carry out in residential setting unfortunately, but detailed observations were made of interactions).

One of the CYP was not able to be directly observed on a second visit, but advocacy took place as part of their decision not to observe, and therefore included. The number of children and young persons observed for the purposes of this thesis analysis was a total of five. Advocates interactions with these children and young people were observed and triangulated with informal interviews and in one case, I also viewed the advocacy report and advocate's own notes.

The parents of two of the young people were spoken to before and/or during the fieldwork informally. Two further telephone interviews with parents who had used advocacy for their child were carried out. There was one returned questionnaire from a parent. (Total of four sets of parents, although not all of their children were observed). The inclusion of parent's views of advocacy and what it meant for their child, was felt to be important to include because the issues of gatekeeping, communication, access to advocacy and the assumed advocarial roll of parents in general.

The children and young people of the ethnographical study

The ages of children and young people in this study covered primary, secondary and post-secondary education provision. The youngest was aged five and the eldest aged twenty at the time of the study.

Of the five children and young people, four were male and one was female. All were white British ethnicity.

Three of the children and young people were diagnosed with autism, and four of the children and young people had other medical needs. All had, or were at the time, accessing psychological and/or speech and language support. Four of the children and young people were actively mobile, the fifth had limited mobility. The particular 'conditions' or 'diagnoses' will not be revealed, as they are not relevant to the study and it is important to maintain anonymity. However crucial to this study is the communication and level of understanding of communication.

The range of communication levels were as follows:

- One young person had limited verbal communication, but used, symbols and gestures to communicate with others, and an iPad when available.
- Three of the young people were not heard to speak but made some vocalisations and appeared to understand instructions to some degree.
- One young person did not verbalise, and it was unclear as to their understanding of instructions.

Three of the children and young people were in residential care and accessing education within the setting. One of these CYP was seen in both school and in the residential unit. Two of the CYP lived with their parents on a full-time basis, however one also accessed respite care.

The children and young people were seen in the total number of eight settings between January and June 2018.

The advocates of the ethnographical study

The advocates of this study were all white British. Three of the advocates were female and one was male. They represented two advocacy agencies.

The advocate's experience ranged from over ten years in advocacy to three months. All had training in advocacy with children and young people through the agencies they worked for and had had training in 'non-instructed advocacy'. Two of the advocates were in senior roles in their respective organisations and supported colleagues in 'non-instructed' advocacy as well as their own case work.

The settings of the ethnographical study

Throughout the study, one family home, three schools, one respite centre, one post eighteen provider, and two units within a residential care setting, were visited with advocates.

Three separate geographical areas were covered, representing three separate local authorities. However, three of the children young people were accommodated outside of their local authority.

4.4. Semi-structured Interviews with Advocates

Initially this methodology was not proposed but was initiated due to the difficulties and limited time of the ethnographical methodology. Whilst I had two

cases, I felt that the number was too small to draw conclusions with conviction or validity. Recorded semi-structured interviews with advocates with 'non-instructed advocacy' experience was proposed using vignettes to replicate cases and met with ethical approval (see Appendix 1). This methodology also enabled a broader perspective on the practice of advocacy by advocates with 'non-instructed' advocacy experience.

Rationale

The use of the vignettes for part of the interview enabled the issues of advocacy and non-instructed advocacy to be examined with the interviewee with three given cases. Vignettes have been used in social work training and practice to explore judgement making, values and social work ethics (Taylor, 2006; Wilks, 2004). If vignettes are realistic and as close to real life situations, studies have shown that responses given to the vignettes are likely to be predictive of the response the participant in real life (Jenkins, Bloor, Fischer, Berney & Neale, 2010; Hughes, 1998).

Care taken in designing the vignettes can increase reliability and validity of the responses (Steiner, Atmuller & Su, 2016). Hughes & Huby (2004) support the use of expert input to provide internal validity and plausibility. For this reason, the design of my vignettes encompassed the issues raised from the cases I had been able to observe or discuss with advocates to the point of design, and my personal experience of 'non-instructed' advocacy. The issues within the vignettes were then validated by the two advocates whose work I had been observing. Common issues were woven into the story of three individual children and young people in advocacy situations with opportunity for the advocate being interviewed to elaborate and illustrate from their own experience. The Vignettes can be found in Appendix 4.

The use of semi-structured questioning is recognised as a valid means of enabling the participants to relate to their own experiences and explore values attitudes and barriers (Gourley, Mshana, Birdthistle,, Bulugu, Zaba & Urassa, 2014; Hughes & Huby, 2004). Vignettes also act as a base-line and common thread from which variance of approach and understanding of policy, practice, legislation and theory, can be identified from the interview responses (Hughes and Huby, 2004; Jenkins et al, 2010; Wilks, 2004), as all participants will be faced with the same issues.

Alternatives considered

Whilst discourse analysis may be appropriate for interviews in other contexts, the focus of this research is the concepts behind and the approach to advocacy for advocates, and the experience for the children and young people themselves, therefore the intricacies of language used in itself, is not the focus. Interpretative phenomenological analysis (IPA) could have been appropriate for this research in that the meanings given by the participants to the subject and events is important to understand i.e. advocates to the meaning, value and understanding of advocacy. However, because the interviews were an additional source of information and not my initial methodology, and because I used vignettes to draw out the processes, approaches and understanding and skills, IPA is considered to be too in-depth and time-consuming for the stage and time available and researcher capacities of this particular research.

When considering the format and ethical issues arising from advocates talking about their personal experiences of cases, the use of vignettes was an appropriate way to ensure issues were covered and advocates could describe their approach and experience without disclosing personal details of cases they have worked.

Conducting the Interviews

The structure of the interviews as a whole, was designed to enable both demographic information to be gathered and a sense of the experience and understanding of advocacy of advocates. Their approach, understanding of theory, policy and legislation were hence recorded. In addition, questions about how they describe non-instructed advocacy and their opinions of the challenges and opportunities of non-instructed advocacy were asked in order to assist in building the bigger picture of the concepts of advocacy and 'non-instructed advocacy' for disabled children and young people - a central aim of this research.

The specific questions asked and prompts given where necessary can be found in Appendix 5.

Advocates were asked to confirm for the record that they were happy to be interviewed and had read the information sheet and consent forms. At the end of the interviews, advocates were asked if they were okay. It was also reiterated that if they wanted to ask anything about the study, or withdraw, they could email or phone on the contact details given.

Questions	Relevance
Age and ethnic background and Language	Potential influence on attitudes/values
Experience outside of Advocacy	/understanding/knowledge and skills
Experience in Current role – including experience with disabled children and young people and ‘non-instructed’ advocacy’	Potential for experience and training to influence in role
Training for the role of non-instructed advocacy	
Dylan	Communication Parents Conflict of interest Professional Barriers Multi-disciplinary team ¹⁵ working Resources Education, Health and Care plans
Billy	Multi-disciplinary team working Safeguarding Communication Transition planning and legislation Looked After Child
Shabnam	Language and cultural issues Advocacy for family Confidentiality/dignity Resistance Multi-disciplinary team working Medical issues
Definition of non-instructed advocacy	Practitioner approach
Challenges and opportunities of non-instructed advocacy	Open ended to allow for further discourse

Table 2 Structure of interview and areas covered

¹⁵ Term for professionals from different disciplines working together. Can include speech and language therapists, physiotherapy, occupational therapy, education, Mental Health professional, educational and/or clinical psychologists, social workers.

Challenges of this methodology anticipated and encountered

Recruitment of advocates

Having had contact with several agencies as the result of the issues with the ethnographical study, I had contacts with four advocacy agencies. The CEOs or senior managers of the agencies agreed to disseminate the information sheet and initial contact form to advocates as appropriate. The initial contact form required the advocate to make contact with myself in order for me to then arrange interviews directly, thus ensuring the recruit's participation was solely on their individual consent, without pressure from the agency to participate.

Potential recruits were offered the opportunity to either conduct the interview over the phone or face-to-face interviews. Phone calls are a significant part of an advocate's daily routine and was anticipated that the familiarity with telephone calling would therefore not be a significant barrier to dialogue during the interview process. Indeed, all advocates chose to be interviewed over the telephone.

Two advocates who enquired about participating withdrew before being interviewed. No advocates withdrew consent after interview.

Confidentiality and ethical considerations

A major concern of agency managers was the issue of confidentiality and the protection of the identity of third parties from whom consent would not be possible to obtain that may be disclosed by advocates during interviews. The proposed use of vignettes overcame some of these concerns.

It was hoped that advocates would feel free to express their opinions because the interviews were confidential. In the letter to potential participants, it was

made clear that their contributions and all responses would be anonymised, and no information passed on to their agency except in the case of safeguarding concerns as per ethical guidelines (Coventry University ethics).

Practicalities of interviewing advocates

Because of the use of two and three-part vignettes, it was necessary to ask advocates to either read or have read to them additional statements. Advocates were advised of the need of laptops/mobile devices during the interview to receive these additional statements via email. I was aware that advocates should have sufficient time to be able to either read or process what they have heard without undue pressure. For this reason, at the start of the interview I explained that I would turn off the recording device and that they could have as much time as they wish to think and write notes if necessary, before resuming the interview. Whilst in the field an advocate may not have time to make decisions regarding their immediate thoughts and actions when faced with the case, nevertheless it was hoped that this methodology would enable advocates to consider and imagine themselves in that situation and draw on their experience.

Only one advocate said they felt imagining the vignettes was difficult. I bore this in mind when transcribing and using data from this advocate. The other advocates were very positive about being interviewed and many felt the vignettes themselves and the issues raised resonated with the challenges of their own experiences.

Transcription of Interviews

Burke, Jenkins & Higman (2010) consider that the practicalities of transcribing interviews need to be guided for the purpose for which the interview data is to be used. I did not need names and the geographical areas to be transcribed but recorded separately, for confidentiality and data protection. The experience of

the advocate was important but did not need to be transcribed verbatim. Table 3 outlines the details of the transcriptions and the rationale.

Section of Interview	Level of detail	Rationale
Introduction, age, ethnicity, languages, disability	Basic notes	Facts for demographical analysis if necessary
Experience before advocacy, advocacy experience and training	Transcribed loosely- details but omitting repetitions and pauses	Important detail, but analysis does not required record of hesitation, uncertainty, need for clarification or prompts
Vignettes and opinions of advocacy	<p>Detailed transcription- mostly verbatim.</p> <p>Capturing prompts by interviewer.</p> <p>Cases cited other than vignettes to be transcribed sensitively with anonymity protected.</p>	<p>Advocates own words to inform research</p> <p>Details of clarification and prompts etc. may be useful in final analysis.</p> <p>Protection of anonymity as assured</p>

Table 3: Summary of transcription detail of the interviews with advocates

Adaptions

Whilst it was anticipated to use exactly the same vignettes for every advocate, changes were made to suit criteria and ways of working of the individual agencies to reflect the practice of that advocate. For example, the age of the young person to sixteen plus for advocates working with adults only. By allowing slight adaptions to the vignettes, it was hoped that all advocates would be to relate to

their own experience. This is in line with previous studies that show vignettes have the best results when reflecting real-life situations (Jenkins, Bloor, Fischer, Berney & Neale, 2010; Hughes, 1998).

The participants

Advocates were drawn from four organisations, covering ten geographical areas of England. Two were self-employed through an advocacy organisation. The contracts under which the advocates worked varied:

- Two advocates only worked with Looked After Children.
- One advocate only carried out residential visiting advocacy.
- Two advocates worked for adult advocacy services.
- Six advocates did both case 'issue-based' advocacy and residential visiting advocacy.

The age range of the advocates was between thirty and seventy-one. The median was aged forty. All were female and white British.

Advocates experience of working as an Independent Advocate ranged from two years to twenty plus years, although two advocates with over twenty years experience, stated their experience was not exclusively within advocacy services.

All advocates had had at least some training in general advocacy:

- Most had attended a two-day training in general children and young people's advocacy, but two advocates said their training had not been for some time.
- Three of the advocates were adult advocacy trained, two of whom had had specific training in advocacy under the Care Act 2014, and 'watching brief'.

- Seven of the advocates had had no specific 'non-instructed' advocacy training, although some mentioned they had had two hours within generalised advocacy training.
- Several mentioned the use of peer support and webinars to update their understanding of working with 'non-instructed' cases.

Six of the advocates had substantial experience but three of the advocates had very little experience of working with children and young people with complex communication needs (under the umbrella of non-instructed advocacy).

All advocates had worked with either children, and/or people with learning disabilities and/or disabled people prior to working as an advocate. The significance of the advocate's experience and training in advocacy will be considered in chapter five and again in chapter nine.

4.5 Data analysis

The data collected in this research utilises mixed-methods; recorded semi-structured interviews, records and reflections of informal conversations, case notes, observations utilising observation framework and detailed snapshots of interactions as well as a review of the available literature of advocacy with disabled children and young people in the UK. The data gleaned from the observations, interviews and literature once gathered was analysed in order to discuss and draw conclusions. Thematic analysis of the data was considered to be the most appropriate method for analysis of the collected data to enable the themes of advocacy to be examined across the methods used for data collection.

Triangulation through the use of data from more than one source, enabled confirmation of themes (Galman, 2013; Bryman, 2012). Thematic analysis enabled the contents of the recorded interviews with advocates to be used

alongside the observations and reflections from the ethnographical observations of advocacy interactions in order to focus on the micro level of the child or young person and advocate relationship.

The thematic analysis of the available literature that met the criteria, also enabled the wider picture of advocacy access and provision to be understood. Within the ethnographical element of this research, several pieces of information from different sources focussed on the same event of advocacy interaction - what was observed myself, discussed with advocate and reported by advocate, thus enabling further triangulation.

Induced and deduced data

Within the context of thematic analysis, the question of whether themes are induced or deduced, needs to be considered. Grounded theory is primarily a bottom-up (induced theory) approach, where themes within the research immerse from the data itself. As Best (2014) infers, even with ethnographical narrative accounts, the process of gathering data whilst being immersed in the field is a process of sifting and prioritising based on own perceptions and priorities and therefore when writing up, the themes that emerge cannot be totally separated from internal hypothesising (deduction) of the researcher. Indeed, my approach to the ethnographical observations through developing the framework of *descriptive*, *interpretive* and *contextual* elements, are indicative of my understanding that a structure was necessary on which to hang my observations. In developing my own framework to fit with the particular subject and participants of the research, I had already made assumptions and hypotheses.

A certain amount of 'internal hypothesising' also applied to the formation of the interview structure and vignettes. I based the scenarios for the interview vignettes on the conversations I had with advocates and my own experience as

an advocate, as well as issues other researchers had identified emerging from my literature review. However, it is possible to see that I had *induced* themes from the evidence I had gathered to this point.

Galman (2013) indicates that many qualitative researchers use both induced and deduced themes to draw together to formulate a theory. My data analysis cannot be separated from the methods of data collection, nor the literature review and my own experience. Thus, I consider that my data analysis will draw on both induced and

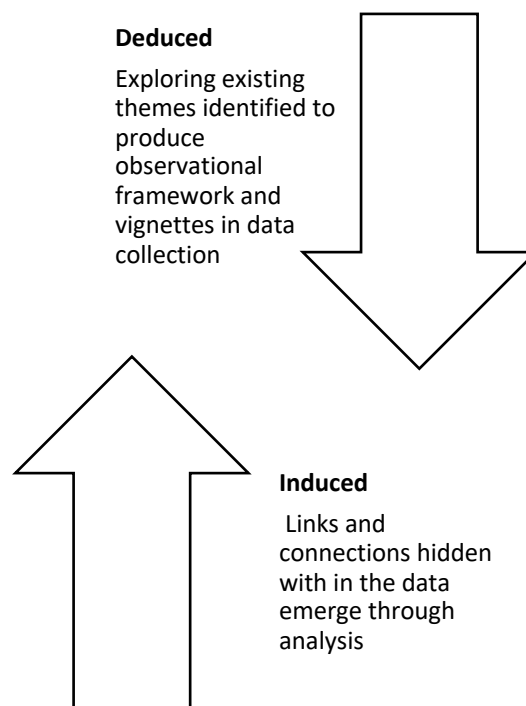


Figure 8: Induced and deduced themes

deduced themes to develop an overall conceptual framework of advocacy for children and young people with complex communication needs.

Analysis of literature

The fieldwork data analysis and the data from the literature review were completed at different times. As previously indicated, the initial literature review was conducted early on in the research in 2017, with a later update in late 2019. For the literature review, I wanted to capture certain information prior to analysis such as demographics and purpose of the report or paper. However, I was also open to inducing evidence from the data, thus themes such as ‘parents acting as advocates’ emerged. NVivo software was used for the literature review to aid analysis.

Analysis of fieldwork data

After all interviews were transcribed from advocates, all observations carried out and follow-up interviews with parents or advocates completed, the data was uploaded onto NVivo software. The data from the direct observations of advocacy work and associated documentation was kept separate from the transcriptions of interviews with advocates using the vignettes. This was to ensure that when it came to analysing attitudes, reactions or thoughts around advocacy actual advocacy practice would be distinguishable from presumed practice of the vignettes. Whilst one would hope that practice from fieldwork data would reflect what advocates would say in the vignettes, it was too early to determine this.

Initially, sample interviews were coded. Some initial codes were entered. This was because the vignettes were specifically designed to extract certain elements of advocacy practice, and all advocates were asked certain questions such as their definition of 'non-instructed' advocacy. Further coding was entered during the process as it emerged.

The observations and reflections of fieldwork were coded, however, at this initial stage the codes were not pre-empted. Nevertheless, there were some striking similarities between the codes at this stage. It was clear that the data covered advocates thoughts, their initial reactions, their reflections on the wider implications of both the practice and policy legislation, as well as issues of advocacy working within social care, education and health and with families.

From this first stage of data coding, a structure to the overall analysis of the advocacy both observed in practice and understood through the interviews with advocates was drafted. This was important at this stage because of the vast amount of data and the potential for losing focus within the analysis. The coding and structure were discussed with my supervision team.

I was aware that my data could be used in various ways, but the focus of my thesis was the practice of advocacy with individual child and young person. Whilst issues of how advocacy is practised in the context of the community and policy and legislation, no previous research has looked in fine detail at the actual advocacy relationships themselves. Thus, I felt compelled to start at this microlevel of my data, but with a mind to the context of advocacy and the purpose of advocacy. It was clear that, particularly for the microlevel of the advocacy relationship, continued analysis would be necessary, and further levels of coding developed from the first level coding before attempting to draw conclusions from the findings. This included coding for 'expression, support and regard'; the three elements of participation outlined in Article 12 of the UNCRC.

4.6 Critic of methodology

There are limitations to the chosen methodologies and the research as a whole.

The literature review

One of the biggest difficulties with the literature review was in finding the documents as the majority were grey material and not found through academic search engines. Despite re-checking right at the end of writing up this thesis, I was surprised to see that one document I was aware of (Longfield, 2019) was indeed only one of two that actually fulfilled the criteria. One of the criticisms of the literature review could be that I did not include advocacy agency material concerning non-instructed advocacy. However, this was because these were published for information only and not reports or policy documents.

The review did not include literature from outside the UK. I excluded non-UK publications as I realised that legislation and policy towards children and children's rights varied. However, this also is true for Scotland and Northern Ireland, and partly for Wales. Nevertheless, some of the documents were not

specific to England, but were UK and therefore documents from Northern Ireland, Scotland and Wales were not excluded, although the differences are noted in the analysis.

I had considered that perhaps the criteria were too narrow as there are many academic articles around disabled children and young people's participation, particularly published in the last few years. However, there is little publication specifically concerning disabled children and young people *and* advocacy, despite a number of articles around *participation* for disabled children and young people. Advocacy is a tool for participation, yet advocacy was still not featured.

The nature of the grey material collated lent itself to narrative review. I may have alternatively carried out a systematic review or meta-analysis of disabled children and young people's participation within academic articles, but this thesis is focused on *advocacy* and there is little bridging between advocacy and academia at present.

Case studies

Only five cases were analysed despite nine children and young people being observed and thirteen parents giving consent. Because of the nature of visiting advocacy in the residential setting, five the children and young people were not able to be observed within the timeframe and because of school holidays. Of the seven children or young people observed in the residential setting, four of them were only observed once and the advocate did not wish to talk before or after the visit.

Given the small number of issue-based cases (two) that were able to be observed, focusing on the three children and young people who had two or more visits seemed appropriate. Overall, I would have preferred to have had more issue-based cases, and/or another residential setting to give a wider base for

data analysis. However, this was not possible in the timeframe. Whilst I had started the process of ethical approval and approaching advocacy agencies early in my doctoral journey (February 2017), my final visit took place in July 2018.

Because of the small number of children and young people within my ethnographical study, care must be taken not to draw too many conclusions as to the communication of disabled children and young people in general. In my data analysis, I finally decided to focus on the elements of the UNCRC Article 12 'expression, support and regard'. The data, and therefore the analysis and findings, are specific to these five children and young people. The findings are a snapshot. I wanted to focus on and keep the child or young person central to the advocacy process, and yet the findings are significant for advocacy practice with children and young people with complex communication needs in general. Nevertheless, none of the children and young people of this study could be regarded as perlocutionary communicators, and this may be significant and worthy of further research to validate the findings for a wider range of disabled children and young people.

Interviews

The validity of the 'themes' covered by the vignettes was verified by the two advocates I had first observed as 'experts' (Hughes & Huby, 2004). When asked to identify the main issues regarding 'non-instructed' advocacy, their list was almost identical to the one I had drawn up before developing the vignettes. During the interviews, advocates were also asked to comment on their familiarity with the issues in their practice and authenticity of the scenarios presented. Most advocates were familiar with one of the scenarios, and many with two. Several were familiar with all three in the issues raised, but these advocates had more 'non-instructed' experience. Two advocates who only carried out residential 'visiting advocacy', did not feel the scenarios represented their practice in the first part of the vignettes when referral was covered. When

drawing up the vignettes, I had not carried out the ethnographical study with the advocates at the residential school. I was also under the impression that advocates carried out both case and visiting advocacy but had failed to appreciate that this may not be the case for all advocates.

Several advocates said that the referrals from parents and health professionals would not happen in their service which only covered Looked After Children. I had not fully appreciated that some advocates would only be familiar with Looked After Children, particularly as the two advocates I had conducted the ethnographical study with came from services that were open to referrals for any disabled child or young person. However, this may be more a reflection on the barriers to advocacy provision than the vignettes themselves. Nevertheless, the validity of response being predicative of the advocate's real-life response could be impacted by this (Hughes, 1998; Jenkins et al, 2010).

Whilst this was not my preferred method of data collection, there were many benefits to validating the research in terms of gaining wider representation of advocacy practice across England. The number of interviewees significantly increased the geographical area and local authorities represented.

Mixed-methodology approach

An issue with mixed methodology is that there is a danger that the researcher and the research findings become 'Jack of all trades but master of none'. Triangulation through mix methodology can be validating and robust. But it is reliant on the methods themselves being valid and robust. Data drawn from several sources could mean that whilst strong themes become dominant, small but significant detail may be lost.

Mixed methodology was not my original intention. An in-depth ethnographical study of advocacy with children and young people and their advocates was my

original preferred methodology. The literature review was a necessary part of the preparation process in understanding advocacy context and policy and practice within the exo-level and macro-level of the individual child or young person's ecosystem. Its significance, particularly in relation to the latest documents still calling for the equal advocacy provision for disabled children people cannot be underestimated, and I feel its inclusion is justified and makes the overall framework, an intended aim of the research, more robust.

The inclusion of semi-structured interviews became necessary because of the difficulties of the originally intended ethnographical study. Whilst there are advantages to a mixed methodology, there is a danger that the experiences of advocates themselves rather than the experience of the children and young people who are being advocated with, become central to this study. This is something I was very aware of and hoped to overcome in the writing of my finding and discussion chapters.

Diversity Issues

In the ethnographic study, all of the children and young people were white British and four of the five were male. The communication needs of the children and young people were different and represented both issue-based and residential visiting advocacy. One of the difficulties in recruitment in the ethnographical study was the small number of advocacy cases that were suitable and fitted within the timescale of the study. However, the ethnographical study sought not to draw generalised conclusions nor be representative of all children and young people with complex communication needs.

Twelve of the thirteen advocates across the study were female. Again, recruitment of a more diverse participant base was limited by the time, however, it is recognised that there is a lack of diversity in terms of gender, disability status

and ethnicity of advocates in general, as evidenced by recruitment statements on many advocacy agency websites.

Concluding comments

For convenience and clarity, the methods utilised have been separated in this chapter. In reality, the process was not neatly defined into the three areas. For example, it was necessary to do a literature review to gather evidence to put to advocacy agencies for the need for this research at the beginning of the research period. Further evidence published later was added towards the end of the research period.

Whilst five advocacy-child/young person relationships were able to be observed in some depth, there were many challenges, despite ethical approval for this methodology. Adaptions to my research included interviews with advocates experienced in non-instructed advocacy using vignettes to replicate real life cases. I had not anticipated doing the interviews with advocates, this became necessary in order to get a wider picture and to more robustly evidence advocacy practice. Figure 9 is a flowchart of the process of this research.

This chapter has been a justification of the methods used to gather the data from which to draw the evidence as to the practice of advocacy with disabled children and young people with complex communication needs in this country. Part C will lay out the findings in four distinct chapters.

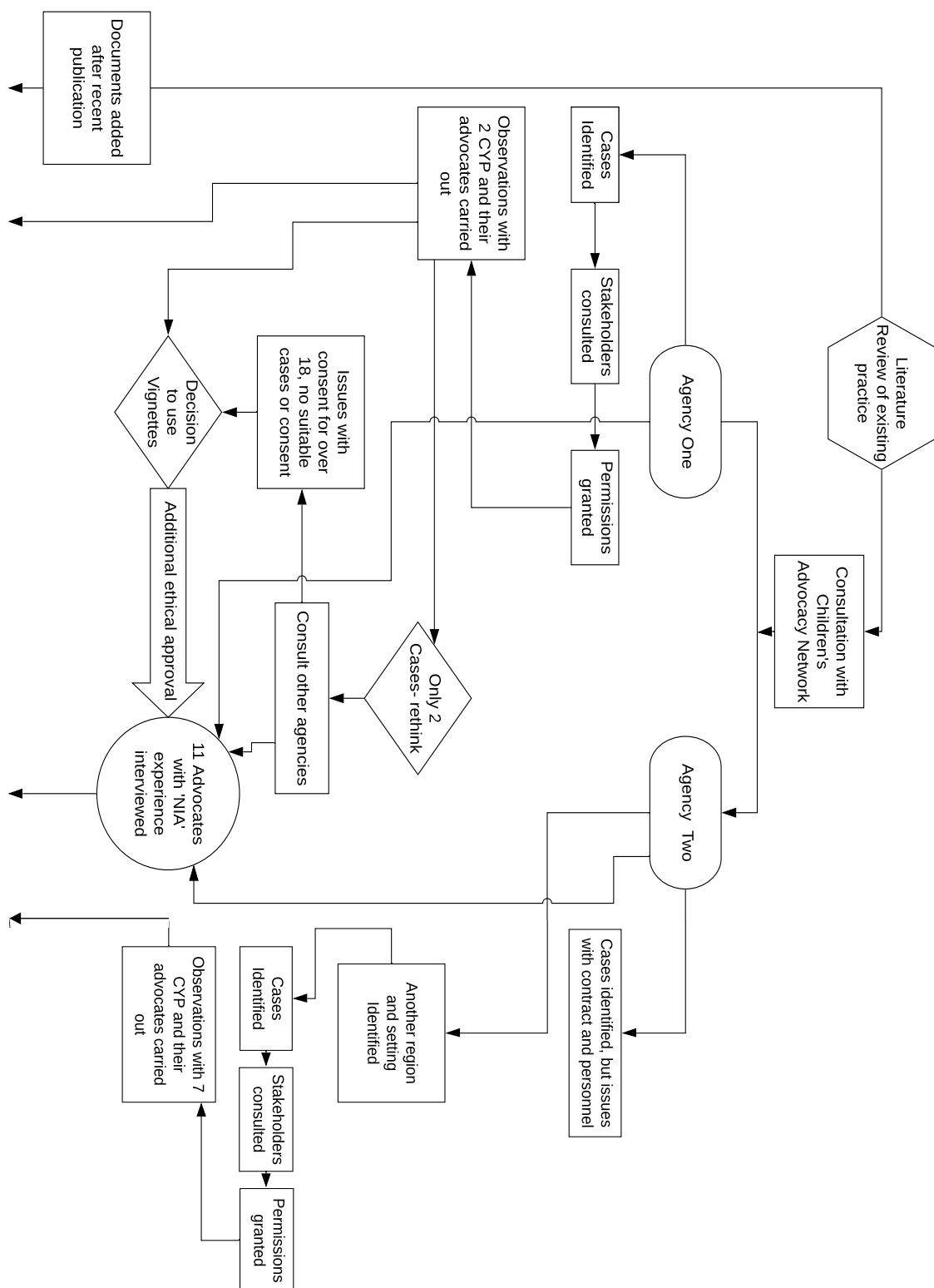


Figure 9 : Flowchart of data collection

Chapter Five:

Evidence and findings from the literature of advocacy and ‘non-instructed’ advocacy for disabled children and young people within the UK

Chapter 4 described and discussed the methodologies used to gather and analyse the data for this research. Data from the three methods of data collection were kept and analysed separately, although for the interviews with advocates and the ethnographical study, coding was matched, and the findings are combined within three of the ‘findings and discussion’ chapters.

The findings and discussion chapters for the fieldwork use the conceptual framework (Figure 1) to explore ‘Expression, support and regard’ as discrete elements of Article 12 in three chapters. These elements of participation for children and young people with complex communication needs within the study are considered in context of their ecosystem, using systems theory (figure 5) as a theoretical framework.

In chapter three, the development, variety and range of advocacy in the UK, in particular England, was outlined. In this chapter, advocacy with disabled children and young people with complex communication needs specifically within the UK will be discussed.

5.1 Discussion of Literature Gathered

In Chapter 4 (Methodology section 4.2) the ‘systematic’ search for, and selection of, literature for this chapter was outlined, and the limitations of the literature search methodology discussed (Methodology section 4.6). Before discussion the findings from the literature gathered as to the evidence of advocacy and non-instructed advocacy with disabled children and young people with complex communication needs, the literature data itself will be critiqued.

Demography of Literature gathered

Thirty-two documents were selected using the criteria outlined in Chapter 4. The earliest documentation *specifically* addressing advocacy and disabled young people was Priestley’s report of 2001. The latest document is from the Children’s Commissioner for England (Longfield, 2019).

Most charity reports and non-governmental reports focussed on Advocacy within England. However, of the seventeen government department or Children’s Commissioner commissioned reports, four concerned advocacy in Wales and three concerned Scotland. Only one document focused on Northern Ireland. It should be noted that Social Care and Child Protection Legislation and Advocacy Guidelines and Standards are not the same across the provinces, although all provinces have all ratified the UNRC guidelines regarding Children’s Rights (England in 1993) and children and young people’s participation in decisions about their care. These differences may be pertinent to consider in

detail of provision, reporting and guidelines for advocacy with children and young people within the provinces. The focus of analysis is primarily on provision in Wales, Scotland and England as only one document relates to Northern Ireland.

Type and focus of document

- Seventeen documents were reports for government agencies or Children's Commissioners.
- Eight reports were written by charities carrying out advocacy, particularly The Children's Society (four documents).
- The remaining were peer-reviewed articles (2), academic thesis submissions, university research department reports for other charities and one chapter of a book.

It should be noted that the majority of documents found were not peer-reviewed. However, if robust quality assessment within a formal systematic review had been conducted, there would be very little data to analyse. Many documents had been written for a purpose other than academic research, yet as narrative documents, they paint a picture of advocacy within the UK.

Whilst all documentation addresses advocacy with disabled children and young people, the purpose and focus of the research or report determines the extent to which the overlapping elements are addressed.

- Three documents addressed disabled children with some reference to advocacy (CQC, 2019; Pinney, 2017; National Working Group on Safeguarding Disabled Children, 2016).
- Nineteen documents addressed advocacy for children and young people in general with varying degrees of reference to disabled children and young people.

- Only nine documents specifically focussed on advocacy for/with disabled children and young people.
- One document was a narrative of person-centred care for children and young people with complex needs including disabled children and young people.

Collection of data within literature gathered

Many of the reports commented on the poor availability of information of access, entitlement and demographic data around advocacy provision (Longfield 2016, Woods & Selwyn 2013, Brady 2011, Franklin & Knight 2011). Whilst some of these are related to research several years ago, even the most recent reports by the Children’s Commissioner for England and Commissioner for Wales reported continuing difficulties with some agencies recording robustly, whilst others less so. A further report by Thomas et al (2017) in conjunction with the Children’s Commissioner (which did not feature in the selected documents), calls for a national system for recording and monitoring outcomes, and better data collection by agencies (Thomas et al 2017). However, it remains to be seen whether data for disabled children, and cases of “non-instructed” advocacy within advocacy for children and young people will be transparent across the UK in the future.

Research participants within the literature gathered

Many documents drew upon research carried out specifically for that report. Some documents were policy documents that used no direct research (Scottish Independent Advocacy Alliance [SIAA], 2016; National Youth Advocacy Service [NYAS], 2013). Many of the reports for the Children’s Commissioner (such as Longfield, 2019; Longfield, 2016; Towley, 2014; Brady, 2011) consulted advocacy agencies and reflected on the purpose of their focus; examining advocacy provision for children and young people in general.

The age of the children and young people within the studies and between the studies varied. Some pointed out that advocacy provision could not be presumed to start at age 0 (Elsley 2010, CC (England) 2016). Townsley et al (2009) focus was on transition services which by definition, means young people aged 15 and above. In contrast, within the scoping studies (Brady 2011, Elsley 2010, Longfield 2019, 2016) consideration was given to children only up to the age of 18, apart from Wales government report examining advocacy from 0-25 (DCELL 2011). Transition planning in England extends to the age of 25, and whilst some of the reports do acknowledge advocacy services and provision beyond 16 or 18, many point out that provision over 18 is both beyond the remit of their study and that of the service provision of the agencies within their studies (Longfield 2016, Wood & Selwyn 2013).

The 'voice' of disabled children and young people in research has already been noted as being less 'heard' than that of their non-disabled peers. Whilst some research consulted children and young people as well as advocates and other professionals (Towley, 2014; Elsley, 2010), the evidence for the participation of disabled children and young people was very limited within most research by government agencies. Charities such as The Children's Society and academic research however, more readily looked at the experience of disabled children and young people in relation to advocacy by direct research with disabled children and young people themselves (Franklin & Knight, 2011; MaCarthy, 2009; Knight & Oliver, 2007). The research carried out towards the two thesis submissions also involved direct research with disabled children and young people (Fields, 2009; Dalrymple, 2003). One document concerned examination of existing research of advocacy during transition planning for disabled children and young people, using peer reviewed and grey material (Woods and Selwyn, 2013).

From analysis of the documentation, several themes emerge to consider regarding current advocacy provision in the UK.

The remaining sections of this chapter are as follows:

- 5.2 Who Advocates?
- 5.3 Independent Advocacy Provision
- 5.4 “Non-instructed” advocacy

5.2 Who Advocates?

Advocacy is not just provided by independent advocates under statutory measures. Parents and other professionals are often in the position to, or are obliged to, act as advocates (Krueger et al, 2019, Burke & Goldman, 2017; Wynd, 2015; Boylan & Dalrymple, 2009; Bateman, 2000) Therefore, the evidence of *who* advocates for children and young people was important to draw out.

Parents¹⁶

Within the literature there was a general acknowledgement that, in relation to social and health care, parents often advocate for their disabled child (Adams et al, 2017; Longfield, 2017; Brady, 2011; McGrath, 2010) and that advocacy is more often provided by the parents of a disabled child than independent advocacy (Brady, 2011; Elsley, 2010; McGrath, 2010; Townsley, 2009). However, Fazil et al’s study (2004) reveals that parents can be in a position when they are not aware or able to access services and where other factors are impacting on the family and thus the child. Fazil et al ‘s study (2004) implies that if parents are advocating for their child, awareness of the rights and services available is essential and furthermore, advocacy support for parents can impact directly on the rights and wellbeing of the child or young person.

¹⁶ Parents refers to people in a parental role, including foster parents within literature gathered.

Parents advocating for their children and young people may be problematic particularly in transition planning; the planning in preparation for adulthood, leaving school and entering adult services. The rights of young people change by law, and professionals are expected to consider the young person's voice, not their parents. Parents find this difficult when their views as parents may conflict with that of their child. Indeed, the young person's voice may not even be considered (Elsley, 2010; Knight & Oliver, 2007).

Scotland's Children's Commissioner comments that very often disabled children and people are unable to develop social networks and friendships independent of their parents, and, as a consequence, have difficulty in separating and articulating their views from that of their parents and therefore would benefit from independent advocacy rather than parental advocacy (Elsley, 2010).

Other professionals

There is the acknowledgement within the literature that "advocacy" can be carried out by people other than parents, who may, or may not be independent of services for that young person (Wood & Selwyn, 2013; Scotland, 2011; Elsley, 2010; Morgan, 2008). Woods & Selwyn (2013) cite fears of children and young people that financial and resource constraints may mean their social workers are not always able to properly advocate on their behalf. There is the potential for conflict regarding working towards the child's *best interests*, rather than with the young person's *wishes and feelings*, particularly for those disabled children and young people with complex communication needs (Knight & Oliver, 2007; Elsley, 2010; Townsley et al, 2009). There are guidelines and professional conduct issues regarding advocating and referral for advocacy for nurses and social workers. However, these are not featured in any documents bar Dalrymple's thesis (2003).

Towley (2014) calls for advocacy provision for all children and young people in Wales through existing youth leaders, teachers, etc. who would be able to access training in advocacy and advocating for the children and young people they work

with. This is a step further from the assumption of advocacy being part of an existing role. Morgan (2008) found that children and young people were reporting that two thirds of the people who advocated for them or supporting them to self-advocate were not independent advocates, however Morgan's research did not include children and young people with complex communication needs. Towley (2014) does point to specialist independent advocacy provision being necessary for the most vulnerable requiring specialist advocacy i.e. independent advocacy.

Self, Peer and Group Advocacy

None of the documents looked specifically at self or group advocacy specifically with disabled children and young people. However, several of the documentation highlights the abilities of young people to express their views about advocacy itself as participants in the research (Longfield, 2016; Elsley, 2010; Shane, 2008; Pona & Hounsell, 2012), and importantly disabled children and young people too (Franklin & Knight, 2011; Mitchell, 2007; NICCY, 2008). However, self-advocacy; being able to advocate for oneself, by disabled children and young people is not overtly evident in the literature selected. The complicating factor for children and young people with communication needs in particular, is that of raising an issue as this requires the receiver of the communication to understand and respond appropriately. Additionally, there may be an issue of the receiver's awareness and openness to advocacy.

The use of peer advocacy however was an interesting research topic for Fields thesis (2009). Using verbal disabled young people to advocate for their non-verbal peers led her to the conclusion that peer advocacy could be used in conjunction with traditional advocacy with an adult advocate. The peer advocate raised issues that may not be overt but were nonetheless pertinent to the young person as seen by the peer. Group advocacy was not a feature of any of the documents within the literature.

5.3 Independent Advocacy Provision

Griesbach et al (2013) examining advocacy provision in Scotland confirms the various forms of advocacy available to children and people as above. As with Towley, Children's Commissioner for Wales (Towley, 2014), Griesbach et al (2013) and Brady (2011) recognise that advocacy can be provided by people other than independent advocates. Whilst accessing advocacy should be a choice, he argues that vulnerable children and young people, including disabled children and young people, should be able to access specialist, trained advocates working to set standards and codes of conduct.

The focus of my research is independent advocacy working rather than parental, peer or other professionals advocating for children and young people. Indeed, many of the documents focused on the provision of Independent Advocacy alone. All documentation discussed 'Independent Advocacy' particularly in relation to children in care and most consider current legislation, child protection, and IRO guidelines. References are frequently made to various Standards of Practice and/or provision for advocacy in the region or are the discussion documents around standards and practice of Independent advocacy (Longfield, 2016; Griesbach et al, 2012; DCELL Wales, 2011; Brady, 2011; Elsley, 2010).

The value of independent advocacy appears to be endorsed by many studies; from the perspective of other professions (Thomas et al, 2016; NYAS, 2013; Morgan, 2008), and of children and young people themselves (Pona & Hounsell, 2012; Knight & Oliver, 2007). However, Thomas et al (2016) echo the concerns raised by Brady (2011) and Wood & Selwyn (2013), that evidence regarding advocacy is largely anecdotal. Moreover, the evidence of advocacy specifically for disabled children and young people is limited (Longfield, 2019, 2016; Brady,

2011; Franklin & Knight, 2011). Evidence from the limited research available demonstrate several issues regarding independent advocacy. Whilst some are common to advocacy in general, some appear to be unique to advocacy with disabled children and young people such as communication methods, gatekeeping and reluctance of parents and/or care staff to advocacy, time and resources.

In-house or Independent Organisation provision

Independent advocacy can be provided by ‘in-house’ local authority advocates or tendered to independent third sector organisations. Whilst the number of local authorities commissioning in-house advocacy now stands at 14% for non-instructed advocacy and 30% for SEN and disabilities (Longfield, 2019), several institutions, including residential schools directly commission advocacy provision. Longfield (2019, 2016) Thomas et al (2016), Townley (2014) and Griesbach (2013), raise concerns over the competitive tendering of advocacy provision. Whilst in-house provision could potentially be seen to not be independent of the local authority, independent advocacy agencies are having to focus on satisfying commissioners in order to maintain the contract, which may mean they feel less able to challenge practice of the local authority. Selwyn & Wood (2013) and Longfield (2019) raise the question of the children and young people’s perception of reliably independence. Given that the relationship with a local authority will most likely be from birth throughout their lifetime for disabled children and young people with complex needs, robust and clear boundaries and guidelines around challenging practice may be suggested but is beyond the remit of my study.

Visiting residential or issue based

Provision of independent advocacy for children and young people is, in the main, either on-going; where an advocate sees a child or young person on a regular

basis, most usually in a residential setting, or issue based; when the advocacy relationship is just for the duration of an issue until resolution. It is not clear from the data from many sources whether advocacy works strictly on issue based or on an on-going capacity. Although implicit to complaints advocacy would be the assumption of the relationship being issued based. As yet, there is little evidence as to the most effective approach to advocacy in general; whether ongoing or issued based, although Franklin & Knight (2011) and NICCY (2008) argue the value of the on-going relationship of the advocate for disabled children and young people in care. The findings of the Care Quality Commission in the interim report on restraint in secure units calls for the strengthening on the role of visiting advocates (CQC, 2019).

Griesbach et al (2012), note that service providers are aware of the intensive resources that are necessary to provide advocacy for disabled children and young people, including non-instructed advocacy. This may impact on the ability of advocacy providers to enable on-going provision or just work on an issue only basis. The argument may go further than just financial. Wood & Selwyn (2013) Franklin & Knight (2011), Knight & Oliver (2007), Mitchell (2007) Dalymple (2003) indicate that for many children and young people, particularly disabled children and young people, issues can be multiple and that an on-going relationship can be beneficial to that child or young person.

Across Scotland, Wales and England children's commissioners are examining and measuring outcomes of advocacy and this in future may provide better indications as to the most effective practice, particularly if the record keeping of the disabling needs (i.e. communication) of the child or young person are also recorded.

Entitlement to Advocacy

When a child is in the care of the local authority, there is legislation regarding right to access independent advocacy in certain circumstances. In England, these

are limited to those detained under the Mental Health Act 2007 (England & Wales), and to children and young people who wish to make a complaint (Brady, 2011; NYAS, 2013; Longfield, 2016). The right to independent advocacy is implied in other legislation such as Children's Hearings in Scotland (Greisbach et al, 2013) and Guidelines for Independent Reviewing Officers (IRO's) regarding participation in child protection and Looked After Children reviews, (Brady, 2011; NYAS, 2013). However, none of the literature sheds light as to the instances of complaints by disabled children or numbers of disabled children participating in LAC reviews with independent advocacy support.

It is also worth noting that 68% of children and young people who are in care for the primary reason of disability, are accommodated by the Local Authority under a voluntary agreement section 20 of Children Act 1989 (Pinney, 2017). And indeed, many disabled children and young people are not in care but live with their parents. Whilst many reports are concerned with children accessing advocacy because children and young people are in care, the advocacy needs of disabled children and young people are perhaps wider due to their health and social care and education needs and their care will continue into adulthood. It should be noted that the majority of the documents, with the exception of Longfield (2019) and Franklin & Knight (2011) do not consider the legal rights of young people over the age of 16, for whom the Mental Capacity Act 2005 applies.

It is acknowledged that there may be missing data for young people over the age of eighteen because advocacy provision is not provided by children's services but adult advocacy services. However, this legislation for entitlement to advocacy is nevertheless important to consider.

Accessibility

Accessibility of independent advocacy appears to be an issue for all children. The most recent figures for England (Longfield, 2019), indicate that the numbers of

children and young people accessing advocacy is only 20% considered of those eligible under legislation, and the majority of these are care leavers, not disabled children and young people. Because of the way data is gathered, or not gathered, it is very difficult to find out the percentage of eligible disabled children and young people accessing services. However, Adams et al (2017) report on parents and young people's experiences of Education, Health and Care plans found that 12% felt they needed advocacy support, but were not offered it. This clearly demonstrates that despite an entitlement under guidelines, advocacy still cannot be assumed.

Knight & Oliver (2004), Franklin & Knight (2011) and Brady (2011), all called for the lack of advocacy provision for disabled young people to be examined and addressed. Several years later, it is therefore disheartening that provision of advocacy for disabled young people is still not assumed. Access for children and young people to advocacy appears to be subject to the interpretation of legislation and guidelines in practice, budgetary constraints, and a 'postcode lottery' (Longfield 2019, p. 20).

The Children's Commissioners for both England and Wales (Longfield, 2016; Towley, 2014) and the CQC (2019), point to the concern of children and young people within care, not being aware of the existence or remit of Independent Advocacy services, with issues of accessibility and appropriateness of communication for children and young people. This again was an issue raised several years ago by Brady (2011) and Morgan (2008). Appropriateness of communication both of advocacy's existence, (posters, leaflets etc.) and of accessible communication within advocacy provision itself and skilled advocates, is also an issue particularly for disabled or Deaf children and young people (Taylor et al, 2015; Franklin & Knight, 2011; Brady, 2011; Elsley, 2010).

5.4 “Non-instructed” advocacy

It should be noted that there is no legislation that coins the term “non-instructed” advocacy relating to health or social care. Whilst the term non-instructed did not appear in any abstract, keywords or titles of the documentation, the term ‘non-instructed advocacy’ appears within the text of many documents. However, not all offer a definition. It should be acknowledged that these refer extensively to other research and findings, particularly reports by The Children’s Society (Mitchell, 2007; Franklin & Knight, 2011) or adult research reports such as Henderson (n.d. grey material source) or Macadam (2013). More detailed explanation and research surrounding the provision of non-instructed advocacy, is considered in only a few of the reports or documents.

From the definitions and discussions within the documentation, it appears that there are several definitions but they are consistent in that ‘non-instructed’ advocacy:

- a) Upholding rights of the child.
- b) Is for a person who cannot instruct an advocate directly, either by virtue of their communication needs, and/or their ability to understand and process information (Brady, 2011; Franklin & Knight, 2011; McGrath, 2010).

Evidence of Provision for ‘non-instructed’ cases

In the selected documents, the actual practice of ‘non-instructed’ advocacy has not been examined in detail, although observed and acknowledged. As Longfield (2016) notes, quantifying the numbers of disabled children accessing advocacy across the country remains difficult because of different record keeping and statistical information held by agencies. Therefore, finding the numbers of

children and young people with complex communication needs within these statistics, is not yet possible. As Elsley (2010) states, it is therefore difficult to ascertain whether the provision matches the need, and pertinent to this study, whether the children and young people who have complex communication needs, are indeed able to access advocacy including non-instructed advocacy. From the evidence of the latest report of England's Children's Commissioner (Longfield 2019), the percentage of Local Authorities recorded, reported or *knew* the number of referrals for 'non-instructed' cases were very low. However, the statistic included very young children. Furthermore, there were further categories for 'disabled and SEN' and 'lacking capacity', children with complex communication needs could come under the first, and certainly young people aged sixteen and over may be included in the second category.

Issues of non-instructed advocacy

The need for specialist communication skills and training in non-instructed advocacy for advocates working with children and young people with complex communication needs was highlighted by several studies (Franklin & Knight, 2011; Scotland, 2011; Elsley, 2010; Knight & Oliver, 2007), several years ago. Indeed, several reports including Children's Commissioners cite Franklin & Knight's (2011) and Mitchell's (2007) work when discussing provision for disabled children and young people. It is rather dismaying that both Longfield (2019) and CQC (2019) found that advocates working with the most vulnerable children and young people as still not adequately trained or sufficiently skilled several years later.

The Children's Commissioner for England (Atkinson in 2014 and in 2016, Longfield 2016), alongside the Children's Commissioner for Scotland (Baillie in 2015) raised concerns over the last few years that 'non-instructed' advocacy was not available in all regions or areas of the UK. In the most recent 2019 Children's Commissioner for England's report, 23% of local authorities *did not know* if they

provided a service, and of those that did know this information, 19% declared they had no provision for non-instructed advocacy (Longfield, 2019). It is not clear whether this deficit of specialised provision is due to lack of trained and appropriate staff to carry out the specialised role, or commissioning issues. Longfield (2019) echoes the findings of Taylor et al (2015), Woods & Selwyn (2013), OFSTED (2012) and Franklin & Knight (2011) that also suggest that capacity of advocacy services to provide trained and skilled advocates may be an issue for specialized provision of non-instructed advocacy. However, Griesbach et al (2012) and MaGrath (2010) and Mitchell (2007) also point out that non-instructed advocacy also takes *time* as well as skills, which is a resource that agencies or commissioners may not be willing to fund.

In some documentation, it was clear research regarding advocacy with children and young people with communication needs was evidenced, although not labelled “non-instructed” (NICCY, 2008; Knight & Oliver, 2007; Priestley, 2001). The notion and concept of “non-instructed” advocacy as a term and the legitimacy of “advocacy” facilitating communication for profoundly disabled children and young people who appear to have little or no intentional communication (NYAS, 2013) will be considered in further chapters. As previously identified, communication and definition of non-instructed needs to be further unpicked. I affirm my belief that non-instructed should not mean *non-participatory*. Furthermore, the definition of a) communication difficulty – both from and to the child or young person, and b) understanding of person of communication taking place are two discrete areas, and certainly within adult advocacy, there is an issue with misunderstanding of the difference and boundaries and hence definition of ‘non-instructed’ advocacy both by advocates themselves and professionals who refer and work with individuals for whom decisions are being made.

Concluding Comments

From the evidence of the literature available, a number of themes emerged. It is recognised that advocacy can be provided by parents, other professionals as well as independent advocates. Independent advocacy can be provided in-house or commissioned, on-going or issue based. Entitlement to advocacy under legislation across the UK is limited and access to advocacy in child protection, looked after children reviews and children's meetings appears to be subject to interpretation of the guidelines. The percentage of children and young people accessing advocacy who are eligible appears to be very low and the statistics for disabled children accessing advocacy is difficult to determine. Provision for disabled children who require non-instructed advocacy is patchy across the UK, with no provision in some areas despite ongoing calls by children's commissioners and children's charities.

From the evidence, advocacy for disabled children and young people, including what is sometimes described as 'non-instructed' advocacy, it is evident that advocacy for disabled children and young people requires skilled advocates, time and resources (CQC, 2019; Longfield, 2019; Woods & Selwyn, 2013, Griesbach et al, 2012; Franklin & Knight, 2011; Elsley, 2010; MaGrath, 2010; Knight & Oliver, 2007; Mitchell 2007). Crucially, there are inconsistencies in the definition of non-instructed advocacy, and this is one of the questions posed by my research.

It should be noted that when searching for documents, I was surprised at the small number of documents specifically focussing on advocacy for disabled children and young people. Whilst the CQC (2019) interim report does mention advocacy in relation to the restraint of young people with mental health and learning disabilities and/or autism, there is no mention of advocacy in Lehen review report 'These are our children' (Lehen, 2017) concerning disabled children and young people in 'out-of-area' residential placements. Perhaps the

visibility of advocacy as a resource to support the voices of disabled children and young people is not raised sufficiently.

Advocates as a support for the rights of *protection* and *provision* are allured to within the Medway serious case review following abuse of children and young people at a secure training centre (Walters, 2019) and CQC report of 2019. However, although there is a lack of consensus across the UK as to the provision of advocacy in terms of entitlement and access, there is also evidence that advocacy itself may be contributing to this lack of visibility. Advocates are not as skilled or trained as they need to be in order to challenge poor practice (Longfield, 2019; CQC 2019; Walters, 2019). Yet there is a Catch-22 in that training and skilling of advocates may be costly for advocacy providers and for the commissioners of advocacy services- namely local authorities. Longfield (2019) indicates that much of the budgets for local authorities dedicated to advocacy for children and young people in general, is directed to fulfil the statutory obligations to provide care leavers with advocacy services. Disabled children and young people, particularly those with complex communication needs (potentially categorised as ‘non-instructed’), are not equally provided for in terms of independent advocacy provision or access across the UK.

Consideration of advocacy within this chapter has painted the picture of advocacy within the exo and macro-level of disabled children and young people’s ecosystems in general. The following chapters examine the evidence of the practice of advocacy focussing on what advocacy means for the individual.

Chapter Six: Expression; children and young people as communicators

The focus of this thesis is on what, and how, advocacy is practised with disabled children and young people with complex communication needs. My methodology for data collection has been based around what advocacy means for the individual child or young person. Whilst I see the child or young person within their ecosystem, I remain convicted that the child or young person should be as participatory in this study as possible, therefore, they, as individual communicators, are at the forefront.

This chapter focusses on children and young people and their expression; their communication; their voice as the expression of their lived experience in which their wishes and feelings may be conveyed.

The first part of this chapter is an introduction to the children and young people of the 'live cases' of the study. It is a record of my own observations, reflections and information gathering of the child or young person's *means*, *context* and possible *intention* of communication. In many ways, reflecting the role of an advocate without the intention of direct interaction with the child or young person (as per methodological reasoning).

The microlevel of the child or young person and their advocate is then examined with particular focus on the advocate's role to observe and be 'receptive' (Kelly, 2018; Nind, Flewitt & Payler, 2010;) of the child or young person's *means*, *context* and *intent* of communication.

Finally, this chapter considers how advocates work with others in the mesosystem. Coming to a consensus as to the intention and meaning of a child or young person's expressed communication can be contentious (Phelvin, 2013; Lyons, 2003), yet this forms an important part of advocacy working in order to understand an individual's voice.

The sections of this chapter area as follows:

- 6.1 The Voice of the child or young person
- 6.2 Advocate observation and receptivity of communication
- 6.3 Consensus with others in understanding individual communication
- 6.4 Expression; the child or young person as a communicator and advocate as receiver of communication

6.1 The Voice of the child or young person

This first section is a description of the voice of the children and young people of the 'live cases'. I consider the means, intention and context of their observed communication.

Means of communication

There are many different forms of communication other than verbal communication (Ogletree et al, 2011; Bunning, 2004). The observations carried out and recorded for the five 'live' cases revealed different means of communication by the individual children or young people. These were recorded either at the time or directly after observation to be as thorough as possible on the devised observation framework. At this stage, this is an overview of my observations as a researcher as to the child or young person's *expression*, and

not related to the advocate or their awareness of the child a young person's communication.

The children and young people had a range of **vocal communication**. Kim was observed to use speech to ask for new websites when using the computer. The words were single, monosyllabic and sometimes unclear in pronunciation. Kim was encouraged to use symbols to make the meaning of vocalisations clearer to others. Kim however, did not use words when responding to questions, but used gesture occasionally or looked to staff to answer on their behalf.

Rowan spoke some words. Most often single words and generally people's names or other nouns. During the visits, Rowan attempted to initiate communication with the advocate and myself through vocalisations and single words as well as gesture. The pronunciations of single words were not always clear, but the innovation, volume and frequency of vocalisations alongside gesture meant that the intention was clear. Rowan was the most vocal of the children and young people and spontaneously said 'happy' when asked what their favourite song was and it was clear from the facial expression that Rowan understood both question and the answer that Rowan gave.

Tobi was reported to have some recognised words, but these were not evident during the observations made. Tobi was observed to make sounds, although the meaning was not often clear and sometimes appeared to be not directed to others around. Both Tobi and Sasha were observed to hum to themselves. Eden was not observed to make any vocalisations.

Facial Expression such as smiling was typically noted in Rowan and Kim in greeting the advocate. Rowan was the most facially expressive of all the children and young people. Three of the children or young people were known to be autistic. Bogdashina (2004) and Calwell (2012) highlight that facial expression is often both challenging to understand and to actuate for a child or young person

with autism. The low count of facial expression may be attributed to this but could also be explained by observation issues of not always being in a position to see a child or young person's face.

Rowan was reported to have used symbols and picture on iPad, but this was not observed on the two visits. Formalised **gesture** in the form of generic Makaton or Signalong, was rarely evident as a communication method during the observations apart from Rowan signing to eat. Although signing was reportedly used by three of the children or young people. Non-standardised gesture was a method utilised by all children and young people to communicate, often understood by others as the child or young person's own version of signs, sometimes in conjunction with other methods:

... waved and smiled and indicated that we should sit down. Obs B2

Observed gestures included nodding, waving, other hand movements including pointing and moving fingers or using objects to point, turning away or towards. Actions- such as miming and pointing, were utilized by Rowan, Sasha, Eden and Kim:

... able to gesture to get paper to tear up- Obs G2

... indicate that [they] wished to pull feathers Obs C1

Tobi was not observed to mime or use actions/gesture to convey meaning but used **gross action** to elicit response- for example running towards the door or rolling a ball or sitting down in front of the screen. Tobi was also observed to use PEC's and point to pictures when presented with a choice of snacks. This was as a response rather than as initiated communication. Staff used symbols with Eden to indicate instructions, but Eden did not use the symbols to communicate, just gesture and (arguably) through actions such as walking and turning away.

Intention of communication

As an advocate, I would judge that none of the children or young people in the study were working at the 'reactionary-perlocution' level of communication (McLean & Snyder McLean (1998) cited Ogletree et al 2011), but there was a range of understanding and intention of communication. Four of the children or young people appeared to understand instructions to some degree. It was unclear as to Sasha's understanding of instructions, but Sasha was observed requesting through gesture to do a certain activity which was interpreted by carers.

Grove et al (2000) identify various "indicators of communicative intent". These include using eye gaze, movement of self towards another, changing behaviour to elicit response. In my observations I recorded particular incidences where children or young people did not show facial expression but turned towards or acknowledged the presence of another:

At one point Eden came up to me and looked – came very close. I stood still and Eden carried on to [advocate]. Eden then returned and did the same, but slower and appeared more inquisitive. (OBS G2)

Sasha made no eye contact. No acknowledgement of my presence, but did tap hand of Advocate when [Advocate] said hello as Sasha passed the door. (OBS C1)

I also noted when there had been a change of response- this was captured particularly when utilising the detailed observation protocol tool:

Tobi continued to wave chew stick no facial change. No turning towards [advocate.]

A few moments later:

Tobi glances then continues to watch screen.

Followed by:

Turns when [advocate] speaks.

Tobi - longer period of looking at 1 2 metres away. (NVC obs A1.1)

Initiating communication was evidenced by all children and young people to a greater or lesser degree. Eden was frequently gesturing a request; however, this was mostly asking the same question (when was going home-time?). Rowan initiated communication with both myself and the advocate, particularly on the second visit. Although this was potentially an issue as I had not intended to build a relationship with any of the children or young people, Rowan clearly was communicating through actions (taking my hand and leading through the door) and through facial gesture and vocalisations that Rowan intended to tell me something.

	Tobi	Rowan	Sasha	Eden	Kim
<i>Speech - identifiable words</i>		Y			Y
<i>Vocalisation</i>	Y	Y	hum		Y
<i>Facial expression</i>	once	Many			Few
<i>Gesture</i>		Y- frequent	Y	Y- frequent	Y
<i>Symbols</i>	Y- response				Y- request
<i>Other behaviour</i>	Y	Y	Y	Y	Y
<i>Response to instruction</i>	Y	Y	Y	Y	Y
<i>Make a request</i>	Y	Y+	once	Y+	Y

Table 4: The means of communication for the children or young people the live cases

It must be noted that the above table is based on what was observed at the time, and the frequency, length, context and purpose of the advocacy visits varied. As an advocate, I would also consider the evidence of others around the child or young person, written reports and assessments and on-going relationship with the child or young person. The above also does not adequately account for the context or subtleties of communication. “Other behaviour” accounts for a wide variety of actions that could be construed as communication (Caldwell, 2012, Goodwin, 2013, Hannon & Clift, 2013). These included incidences such as the following recorded observations:

Rowan was crossing [their] legs feet over ankles... was then indicating (gesture and word ‘help?’) [their] feet were stuck. The support worker would then interact ...tell [them] that [they] were able to do it [them]self. This happened five times in the space of four minutes. Obs B1

[Advocate] went into the room where Eden was sitting ripping up paper. Eden left the room and went to[their] bedroom. Eden came back into the room then promptly left again....[Advocate] went into the room... and said hello. Eden left the room. (Obs G3)

Tobi ran into classroom, picked up various objects, placed wooden peg in mouth. Obs A4

These will be considered further as intention and meaning may be influenced by context and also open to interpretation.

Context of communication

Waving- movement of the hand, can be interpreted as a greeting in the context of a response to someone entering a room (Rowan). A smile could indicate acceptance in the context of being given something or someone entering the room (Rowan and Kim). It could also be a means to demonstrate response to a question being asked:

Advocate asked Kim what things [they] liked. Kim looked outside. Staff explained Kim liked working with the animals [which were outside], at which Kim smiled. (Obs H1)

These examples assume typical behavioural response, but as an observer, I had no reason to question the intention. However, in my reflections I noted that Kim appeared to be communicating their wishes and feelings and contradict the staff's communication about Kim's reluctance to go outside:

What was interesting was that staff had said Kim did not want to go out; that [they] had been frightened by the incident. Yet, towards the end of the visit, Kim requested to go out (nonverbally). This might have also been to do with the conversation the advocate had with staff member about shoes. It was really clear that Kim was attempting to communicate with [the advocate] and understood the conversation about issues. (Ref VH2)

At times, observing within context of not only the environment, but the time and history and interpretation by people who worked closely with the child or young person were important. For example, when Tobi was observed to move towards the door, this was interpreted by staff to mean Tobi wished to leave the room. Conversely, when Tobi sat down, Tobi wished to stay (Obs A1).

When Sasha and Eden were given the activities they had requested (gesture interpreted by others), they accepted the paper and feathers. Their request was seen in the context of the time of day that they had asked for the activities which was directly after school (Obs C1, G2). Their acceptance was interpreted in context of their normal response to receiving something; it was not seen as a negative response.

Occasionally intention of meaning of the behaviour can be questionable, but the context aids some understanding (Greathead et al, 2016; Simmons & Watson, 2010; Bunning, 2004) Eden repeatedly moved away from the advocate into

another room when the advocate tried to interact (Obs G3). There could be various interpretations for this behaviour: it could be that Eden did not like to be sat by, or did not like the advocate, or liked to move location frequently. The time of the visit however, which was straight after school may offer an explanation for this behaviour in context. Staff reported that Eden usually liked to sit in their room for an hour after school in the dark. Therefore, I would consider that Eden's seemingly avoidant behaviour was because Eden's routine was interrupted, and Eden needed space. Eden was seen in school (Obs G1) and did not avoid the advocate in this context, in fact gestured a question towards to advocate (regarding going home – interpreted by staff).

Rowan reacted, behaved and communicated differently in the first observation compared to the second observation. Rowan's apparent attention-seeking behaviour and repetitive shouting out in one setting has to be understood within the context of the environment (Cold, bleak, crowded) where Rowan had been sat for over an hour doing a repetitive activity (colouring) with no chance of getting up and walking around as the other people were able to do, whilst having the advocates questions being answered on Rowan's behalf by a staff member interrupting. Despite the distractions of dinner preparations in a different setting, Rowan demonstrated a much higher level of communication and understanding, given time and staff encouraging Rowan to answer questions for themselves.

Observation in different settings and times are therefore important and why caution with all the evidence gathered for the live cases must be taken to avoid generalisations and judgements based on snapshots of observations. As a researcher and an advocate, I was able to observe methods of communication and context in which the communication/expression was made at the time and reflect on the potential level of understanding and intention of the individuals. Therefore, data reflects literal, interpretive and reflexive levels (Mason, 1996) of my observations. In order for clarity, I do not intend to further examine the issues

of ambiguity in intentions or meaning of communication of the children or young people at particular incidences at this stage, other than to acknowledge that the observations have been influenced by my values and experience in advocacy and working with children and young people, and also my skills and the tools used to record incidences.

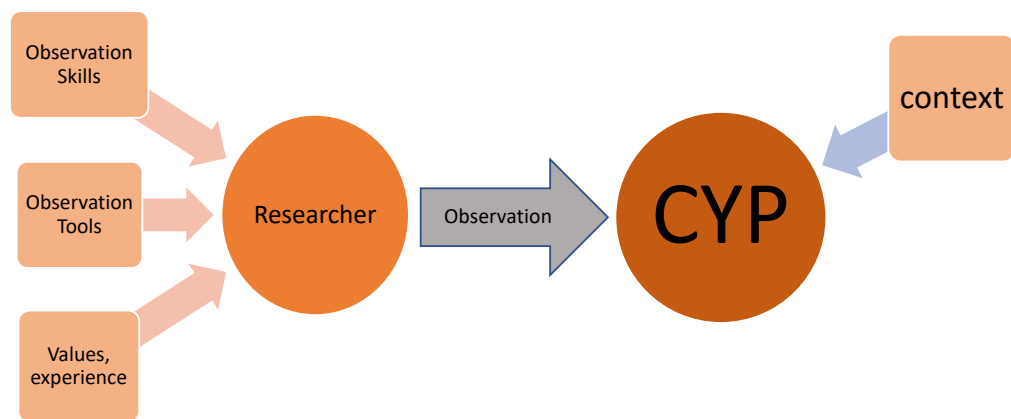


Figure 10: The relationship and influences on observer (researcher) and child or young person

6.2 Advocate observation and receptivity of communication

Attention will now turn to the advocates observations of means, context and intention of *expression* of the children and young people in the live cases. Being able to observe and take note of expressed communication is essential for receptivity and the continuation of communication (Nind, Flewitt & Payler, 2010; Kelly, 2000).

Advocate awareness within the live cases

The distinction between my observations and that of the advocate is important to draw out, as it is the advocacy relationship which is supporting the child or young person to have a voice through the work and *receptivity* of the advocate. The evidence is derived from the conversations post-visit (recorded on observation protocol and/or reflections) and for one CYP, sightings of the advocates notes where the advocate's observations were recorded in detail.

Receptivity

None of the advocacy visits observed were initial visits. The children and young people were all familiar to the advocates, whether this was the second visit or the visit after many months or years of contact with the child or young person. All four advocates were able to indicate to me prior to the visits the level of communication of the child or young person, and to greater or lesser extent, the methods by which the individuals were able to make their wishes known. However, this was not necessarily based on how well the advocate had analysed the individual, but on the circumstances and depth of conversation prior to my first observation visit.

During the observations carried out, all the advocates expressed awareness of the individual child or young person's non-verbal communication, either with a direct response, comments to myself or others at the time, or during post observation conversations.

Tobi's advocate responded through reciprocal actions to Tobi, for example returning a ball that was rolled towards the advocate. Tobi's advocate also throughout the visits, verbally asked Tobi questions or commented on what appeared to be Tobi's communication. When Tobi lay down, the advocate asked whether Tobi was tired. The advocate believed that recognising and acknowledging the actions was important. Nevertheless, Tobi's advocate was

cautious as to drawing conclusions as to *meaning* of actions unless they felt they were clear.

Kim's advocate during the observations responded verbally to vocalisations and gestures that Kim made. The advocate also noticed that Kim appeared to understand what the staff were saying, and we discussed Kim's reactions to the conversations about Kim's footwear and to Kim's apparent reluctance to going outside. Whilst during the visit the advocate did not pursue these reactions with Kim, the advocate had clearly noted them:

Observed shoes and use of crocs to go outside despite one member of staff saying Kim won't go out. (PO A5)

The advocate spoke of their belief that Kim was intending to go out and Kim's action was deliberate and was going to note this in their report.

Many incidences where the advocates responded and demonstrated 'receptivity' to the child or young person also demonstrated *regard* for the child or young person's expression or 'voice'; the advocate enabled 'space', 'audience', and notably 'influence' (Lundy, 2007). The micro-level of the advocate/ child or young person relationship as a conduit for 'regard' will be discussed in greater detail in chapter eight.

Significance of Context

All advocates were reflective as to the significance and meaning of vocalisations, gestures, use of signs and symbol and behaviours for the child or young person they were observing. All the advocates were aware that the non-verbal communication and behaviours of the children and young people were influenced by many factors. Advocates appeared to be aware of **health issues**; for example, one child or young person had recently been ill and another's age and sudden growth indicating puberty, were considered as possibly influential in

the changes of behaviours demonstrated on the visits and reported by others around the individual child or young person.

The **time of day** was noted by the advocates as influencing the communication willingness of the child or young person. Some visits were conducted in the morning, but over half were carried out after school/ college time. This was commented and noted by the advocates for Tobi, Sasha, Rowan and Eden in particular as possibly impacting on the child or young person's focus because of tiredness but also that they were in a routine of doing other activities at this time of day, including for Eden, having time alone in their room. **Temperature and weather** were also noted by the advocates as possible influences- several visits were during the heatwave when keeping cool was impacting staff concerns and activities and routines for the child or young person.

The **physical environment** was noted by three of the advocates to be of possible significance in behavioural changes or communication. For some children or young people, this was the physical difference between settings, for example, busy classroom with lots of other children and young people compared to the home environment. Whilst for Sasha, awareness of the advocate to changes over time within the environment enabled the advocate to draw conclusions as to Sasha's behaviour. Sasha had taken to picking paint and plaster off the walls in recent months, to the extent that it had caused damage to Sasha's fingers. However, this had been after the walls have been painted a different colour. The advocate's interpretation of Sasha's behaviour was that Sasha was responding to the change of wall colour, rather than developing self-harming behaviour.

Seeing a child or young person over time was also viewed as important, both for case and visiting advocacy, in terms of building up a relationship with the child or young person, and also to understand and 'read' their individual communication methods. Advocates also cited the need for visits over a time period particularly when issues may not surface within the confines of one visit.

For example, a visit to Kim came after some issues within the setting and staff were concerned that these might be having a detrimental impact on Kim. Kim's advocate was keen to establish whether there were effects on Kim, and whilst on that particular visit, the advocate determined that Kim appeared to be unaffected, the advocate was still cautious to presume Kim was not affected. We spoke after the observation about gathering evidence from other sources, including staff records and further observation to inform.

Three of the children or young people were observed by their advocates in **more than one setting**. Whilst the visiting advocacy was restricted to one setting, one of the CYP was observed in school during advocate's work with other CYP. This was reported by the advocate to help not only in developing a relationship with the CYP, but also in that the advocate did not rely solely on the difficulties of communication in the residential setting when building an overall picture of communication for this CYP. Advocates working in both case and visiting advocacy expressed the importance of seeing the children and young people in different settings and contexts to get a fuller picture of the child or young person:

... expressed that [advocate] had notice the difference between a's behaviour and demeanour in both settings.

However, this advocate also went onto state that they were:

...careful to avoid drawing too many conclusions from just the two observations of A in the two settings.

Seeing the children or young people in different settings if possible, helped the advocates to build up a picture of the child or young person from different sources. Children and young people behaving differently in different settings can be a means of communication in itself (Greathead et al, 2016; Simmons & Watson, 2015) but can also be indicative of an issue that needs to be addressed (Nind et al, 2010).

The **age** of the child or young person was not explicitly discussed by any of the advocates in relation to the communication methods, however, for the three young people in Key Stage Four and Five, the advocates expressed their concern for the maximum participation of these individuals in the decision made by others regarding plans for the future. Whilst two of the children or young people were seen because of imminent or recent changes warranting case advocacy, three of the children or young people were seen as part of on-going residential advocacy but the advocates all demonstrated an awareness of the issues that change may present and observed and noted these. The use of appropriate communication tools to illicit the individual's wishes and feelings specifically around their future placements and changes were cited as an important consideration by the advocates, regardless of age.

Advocate awareness of expression in vignettes

Whilst the 'live' case studies enabled the interaction of individual children or young people and their advocates to be observed and recorded, each child or young person is unique. Differences in observations and interpretations as to the meaning within the context between that of myself as researcher, and that of the advocate are subjective and reliant on my observations and recording of conversations and events. Giving the same case to several advocates using the vignettes, allows similarities and/or differences of level of observation, interaction and interpretation of communication by advocates to be explored (Jenkins et al, 2010; Hughes and Huby, 2004; Wilks, 2004). Whilst the use of vignettes relies on the advocate to picture in their mind the child or young person and what they would do, most advocates were confident that they understood the cases. All advocates were recruited on the understanding that the research concerns non-instructed advocacy, and that to be eligible for the research they should have had at least one case deemed 'non-instructed'. The first parts of the

vignettes were sent around 48 hours before the interviews. (See Appendix 4 for Vignettes).

There is much information to be drawn from advocates responses to the vignettes, however, for the purposes of this chapter, the focus will be on the advocates approach to communication and the interaction the advocate would anticipate.

Dylan

Throughout the two parts of the vignettes Dylan (aged 10) is described as having severe learning disabilities and autism. He is not observed to be verbal but makes vocalisations. He responds to singing, responded to PECs and verbal, object and symbolic commands. Speech and language services have been involved. In the first part of the vignette, advocates were given the following information:

Part 1

Dylan is a 10-year-old boy who has been referred to your service by his parents. They wish him to have an advocate in order to access further psychological/ Child and Adolescent Mental Health Services [CAMHS] support with his self-biting and increasing aggressive behaviours. They report he has been assessed previously and was given support within school. They are concerned that the advice given to school is not being carried out and school are not helping as much as they can. Dylan has an Education Health and Care Plan review in 4 weeks time. They describe Dylan as having Severe Learning Disabilities and Autism.

When the second part of the case study was presented, making it clear that the advocate had gone to visit Dylan at school, six advocates mentioned direct observation:

I would spend a lot of time observing him and see how he interacts with peers, how he interacts with staff. AM

Five advocates stated that they would use or attempt to use PEC's or communication cards if this was possible. One advocate picked up on the response of Dylan to singing and suggested that one communication method might be through music, and another mentioned play as a means of interacting with Dylan. Another suggested communication through drawing.

While some advocates said that they would try and make direct eye-contact with Dylan, others were cautious to directly communicate and would be led by staff around him. One advocate stated:

It may be that he needs a bit of time to get used to having me there so that I can see, I can observe his usual behaviour rather than the behaviour of someone who is anxious or alarmed at having a stranger sat next to them. AX

The majority felt that they would need to talk to people around him either to gather information about Dylan's behaviour and communication, or what his likes/dislikes were:

There will be a lot of talk about communication around those first visits. I find that out from everybody I spoke to regarding Dylan AL

I find it really helpful to speak to those people who have known him for a longer period of time as well- in terms of what they think he likes, what he dislikes, what makes him happy, what makes them unhappy and how they know those things. AW

When Dylan vocalises and bites himself towards the end of the lesson, six advocates picked up on this but with varying responses:

He was observed to start self-biting when asked to clear up so was this to do with increased noise? AL

Dylan appears to be happy at school, the issues arise when he is not the focus of attention... Would not be up to me to determine what is causing the biting and aggression. I want to know what his assessments were. AT

Three advocates linked the behaviour to communication:

If there has been increased number of incidences or his behaviours have escalated, it is clear communication on his behalf that something is happening; there is something underlying that he is not happy with.... speak to staff to see if there are any patterns they might noticed with regard to self-biting. AM

Shabnam

Advocates were sent the following information prior to the interviews and asked how they would approach the case:

Part 1

Shabnam is referred into your service by the community nurse. She is concerned that mum is resistant to support and Shabnam has had a Percutaneous endoscopic gastrostomy [PEG] fitted recently and several changes of social worker in the last year which has affected respite / short break provision. The community nurse states mum has agreed to advocacy support for her daughter but suggests she may change her mind. Shabnam is 16 years old and has a de-generative condition.

Whilst some advocates were concerned about the issue of mum's apparent reluctance to engage and 'allow' Shabnam to see the advocate, they all eventually came to the conclusion that to speak to Shabnam herself would be preferable. Only one advocate queried Shabnam's medical condition and said they would Google it to find out more. They wondered whether this would impact on Shabnam's communication.

After part two introduced the fact that Shabnam's mother had language barriers, some advocates suggested that Shabnam herself may not have English as a first language.

The majority of advocates mentioned observation and asking questions of others as major features of their advocacy work with Shabnam:

There is very little communication and they can't really tell me their wishes and feelings. It's in a majority- my observations of them and information I'm getting from those around them. AW

Many advocates recognised that Shabnam reacted to her siblings in Part 2, this advocate drew the following conclusion:

'It would appear she doesn't have verbal communication, but we've seen her laughing. It might be that S communication is on her expression and body language- frowning, laughing whether she's happy or not'. AX

Whilst another suggested that:

It clearly states that she interacts with the younger siblings but she's in a wheelchair and she perhaps can't get to them. AM

Three advocates voluntarily spoke about **communicating directly** with Shabnam and how they might go about finding out more about this. Other advocates were prompted, and an additional advocate agreed they would communicate directly with Shabnam if they knew what her responses were.

Two advocates spoke about how they tried to include a child or young person in conversations even if they were not able to respond:

Sometimes I will direct a question at the young person knowing they're not going to answer me but then the carer or parent will answer the question. I try to keep that child and young person in the centre of the conversation so that they know that I am there for them. AL

The mention of **eye-contact** in part three raised many more comments about interacting directly with Shabnam, including from advocates who were less forthcoming or confident in the previous sections:

She is making eye contact with me, I feel that she wants to respond to me, she seems to have taken with me. Because she's looking at me while I'm talking to her, she is communicating with me, isn't she? AV

Looks like she's responding positively. Suggests she understands although she's not able to verbalise things is taking things in that I'm saying. And she is understanding that I am speaking to her. AZ

On reflection after all the information was given, some advocates thought that Shabnam may be able to communicate in non-verbal ways, and that **time** was a feature for advocacy practice:

There is a rapport between Shabnam and the advocate- I don't know enough about the communication she is using, but it's positive. It needs to be taken into account that it will take time. AT

Might just be that it's a start of her relaxing around me- she is getting to know me, there might be another follow-up visit after that just to see after time if she starts to talk about what she wants or doesn't want. AL

Another advocate went as far as to add:

It may be that if I could provide her with some pictures or some written information, she could point what she wants. We could perhaps build on that issue if able to do that, and perhaps use talking mats kind of approach. A bit of trial and error and see what works and build on that...Taking photos or symbols, or app...AX

Billy

Information in the form of the first part of the vignette was also sent to advocates prior to their interviews:

Part 1

Billy is nearly 18. Billy has an Education, Health and Care /Transition planning meeting in 2 months time. You have been asked to advocate for Billy as a 'Looked After' young person with limited communication and a Learning Disability.

When you visit Billy, you use communication cards to help explain your role. Billy repeatedly asks about a sister Trish and ignores the communication cards. You ask Billy if it ok to ask the staff about Trish. You find out that Trish is an older sister. Trish is twenty-four years old.

Some advocates saw Billy's rejection of the communication cards purely in terms of Billy wishing to communicate about Trish. One advocate suggested returning another time to try with the communication cards if this was Billy's usual means of communication. Others questioned the validity of using communications cards with Billy, indicating that the use may not be the best means of communicating with Billy. One advocate questioned the use of communication cards per-se:

The issue with communication cards is that you can't get a sense of what's going on in their head - rather than things you give to them. You can give them options that they may not be on cards. It's about encouraging them to think themselves rather than what is on the cards. AP

All advocates assumed that Billy was able to understand and communicate verbally, only one advocate questioned Billy's understanding and potential capacity in communicating consistently her wishes and feelings:

How much of this (s)he's going to understand would be my first question really. So I will check that out with him and whoever his carers are and his social worker.... It will be ensuring that what he

says is consistent. He might say on the first visit he wants to stay with Trish, but what does he say on the second, third, fourth visit?
AJ

However, some advocates recognised that if Billy was using communication cards, her verbal communication and understanding may be limited and may need other alternatives. Three advocates suggested using iPads and/or emoji-cons as alternative ways of communicating with Billy:

Communication cards... try to make more of them to talk about family, seeing family, questions about family. We do have iPads so I could use those. Or sees it emoji-cons- happy face, sad face to go to what his feeling about that. Just be led by Billy in terms of what he likes and how he wants to communicate. AW

Some advocates thought it was important to speak to other people around Billy about the *issues* of the case, but until Billy reacted to Jake's name by standing up and throwing her chair in part three, speaking to others about Billy's *communication*, did not feature.

Eight advocates thought that Billy's behaviour was a means of communication:

Aggression could be really the only way [Billy] could communicate. I wouldn't take it personally-I'd recognise that she was obviously very frustrated and upset. She can't tell people about it easily. AV

suggests she clearly has views, no, communicating those views, although maybe not appropriately. AT

Six questioned the meaning and several were reluctant to assume that she was directly communicating about Jake:

I would want to speak to her bit more and ask her what happened, why are you angry about Jake. But it might not be Jake, it might be she is fed up of me asking questions. It's about not wanted to jump to conclusions. AW

It could be Billy's way of saying that she is really not happy. It could be a way of saying she doesn't want to talk to you any more. AL

The consequential reactions of the advocates were varied; some thought they should ask more questions, others that they should curtail the session there and then and speak to others and/or return at a later date.

Response	Dylan	Shabnam	Billy
<i>Approach others for information</i>	8	5	3
<i>See in different settings</i>	4	3	1
<i>See at different times</i>	6	3	0
<i>Use observation</i>	6	7	1
<i>Use verbal communication to initiate interaction</i>	4	4	11
<i>Use augmentative and alternative communication</i>	5	2	6
<i>Use other methods to interact (eye contact, play)</i>	5	6	1
<i>Questions meaning of behaviour</i>	6	7	6

Table 5: Responses and approach of advocates to the children and young people of the vignettes

The advocates who had less experience with non-instructed advocacy demonstrated more confidence with the Billy vignette. The quality of response by advocates with the weaker responses to Shabnam and Dylan was notably higher when confronted with Billy. Billy had some speech and was verbally communicating something around Trish that advocates could quantify and build on. Many recognised this may require time but felt that Billy was a 'case they could work with'. Given that all advocates had some non-instructed advocacy experience to be part of the study, this must be considered worrying and something to address for advocacy agencies regarding training for their non-instructed advocacy advocates.

6.3 Consensus with others in understanding individual communication

One of the challenges of advocacy practice, particularly in non-instructed advocacy, is that of coming to a consensus with others about the meaning or intent of non-verbal communication of an individual. Phelvin (2012) suggests a 'reflection in/on action' framework for learning disability professionals working with individuals with profoundly disabled people to interpret their non-verbal communication. A series of eight questions serves as a useful tool for observation, identifying behaviour and interpreting from others. Advocates are encouraged to seek, and are often reliant upon, parents and or carers for information about a child or young person's communication, and its meaning (Smith & Brackley, 2017), particularly when a child or young person is working at illocutionary or perlocutionary levels and meaning cannot be verified through recognised AAC methods.

Advocates for all the children and young people in the live cases conversed with others around the child or young person about the individual's communication during the visits, often in relation to their immediate behaviours. For example:

Tobi sat down in Hall (first Hall time). TA told advocate this was [Tobi's] way of saying [they] wanted to stay.

The advocates for all the children and young people were aware of the knowledge and experience of staff of the child or young person. Sasha's advocate was mindful as to the staff understanding of the subtleties of Sasha's behaviour and their response to changes and issues and the somewhat-protective value of that as far as Sasha's wellbeing. Advocates also spoke to others about the child or young person and their communication when they were not able to observe:

[Advocate asked] for illustrations from staff regarding CYP reactions to leaving mum, and what CYP does during [their] time there. (ObsB 2.2)

Advocate felt that [their] report will be more robust if [they were] able to either see child's interactions with peers as indicated by parents. (Ref A3)

[I did] not observed that- so need to be careful because I didn't see an evidence. (POC 5)

Figure 11 demonstrates this dynamic.

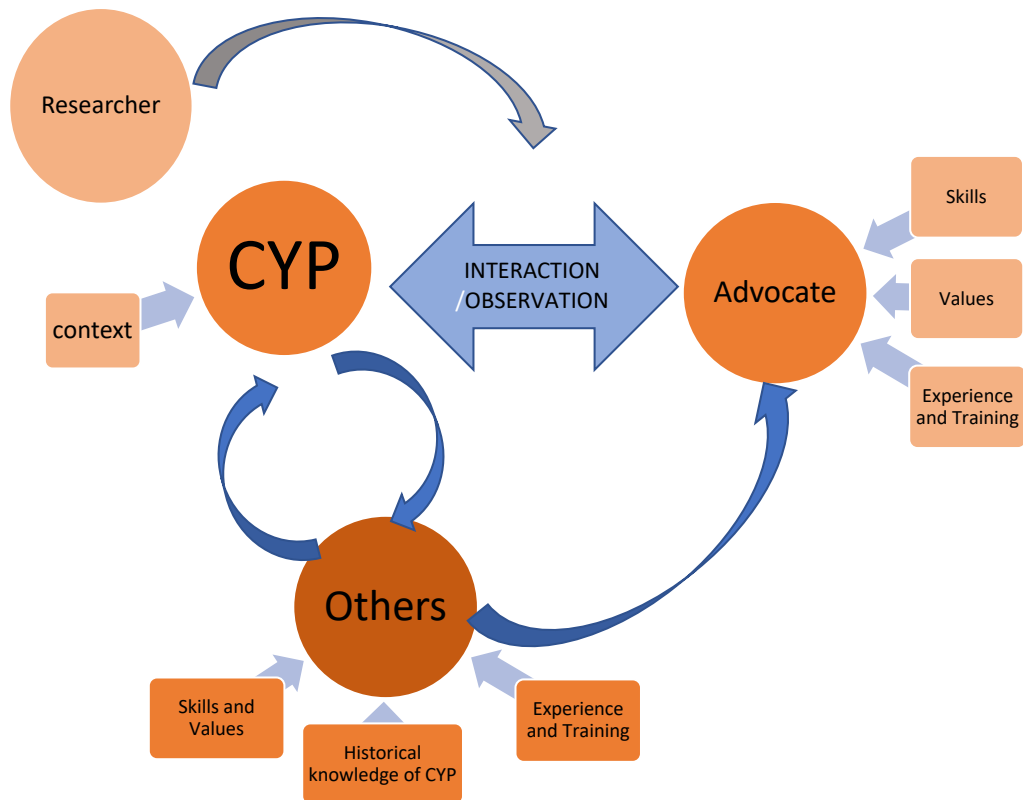


Figure 11 Illustration of the complexities of advocates working alongside others to come to a consensus of understanding whilst still maintaining independence

When asked about the challenges of advocacy, several responses by participants in both “live” observed cases and the interviews, refer directly to issues around the micro-level of the advocacy relationship they had encountered in their advocacy and non-instructed advocacy practice. Many advocates cited the difficulties of observing a child or young person for a short time:

We are only observing behaviours at certain times. AZ

Whilst many felt that seeing the child or young person in different settings was important, sometimes this was limited by the practicalities of time and limits of the advocacy service and the purpose of the advocacy intervention:

I think the obvious one is that I can only get to know a little tiny bit about a particular child from observations...I am very reliant on the staff who are working with that child to give me the information. AK

Advocates were often concerned as to their dependence on the opinion of others, at least initially, as to the meaning and appropriate reactions to expressed communication:

I have observed so many young people where people have said 'oh yeah, you won't get a lot out of them, they don't really communicate' but it is so clear what they like and what they don't like from their body language, from the way they are interacting with people, AW

Conversely, another advocate reported:

Staff...sometimes have very high levels of expectation for the child...I have to take their word for it, I'm not disputing it, but it is open to interpretation...I could not test. AK

In two of the live cases, advocates asked for examples of behaviours in certain situations of the individual child or young person from staff. This was to both to illustrate and collaborate what staff had suggested was the meaning of the communication of the individual. In more than one case, there was a discrepancy between the reported communication by family/staff of one setting and that of staff in another setting. As Greathead et al (2016) and Simmons & Watson (2010) found, this is not unique.

One advocate suggested videoing the CYP at both settings to 'synch' the reception of the CYP communication; the CYP responses were often subtle and it was claimed by one setting to be the CYP own 'sign', rather than what was expected by the other setting. There are times when the advocate and others working with a child or young person have differing views on a child or young person's communication intentions. This is illustrated in Figure 12. This may be

because whilst consensus can be built up between those involved in a child or young person's life (Solodiuk, 2013; Petry & Maes, 2006), different meaning can be attributed within different contexts or settings (Simmons and Watson, 2010). Non-verbal communication is often interpreted through tacit intuition rather than explicit knowledge (Phelvin, 2012) when a child or young person is familiar to carers in a setting for example.

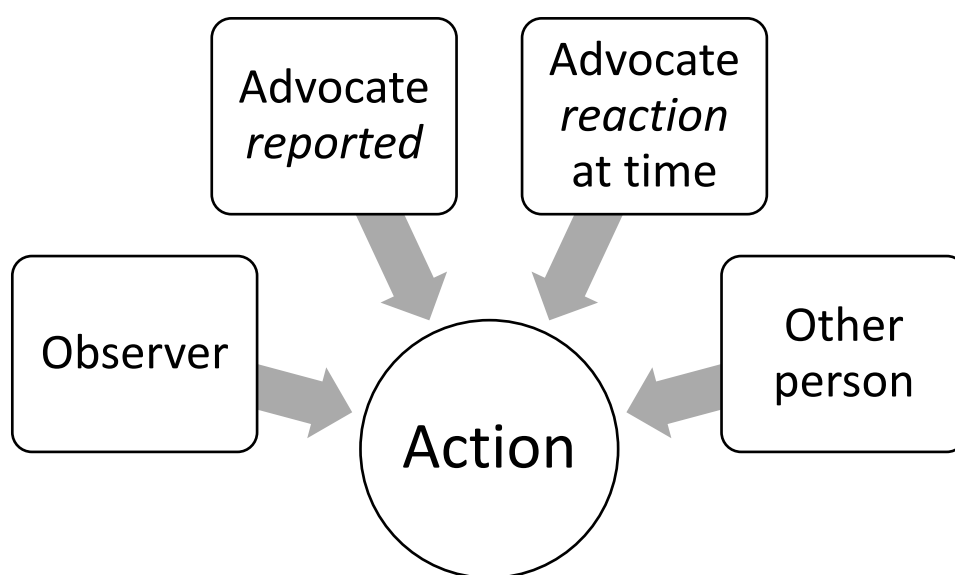


Figure 12 How one action of a child or young person can be both reacted to and interpreted differently as the event happened, was recorded and reflected upon by different individuals

The following figures are examples from the 'live cases'.

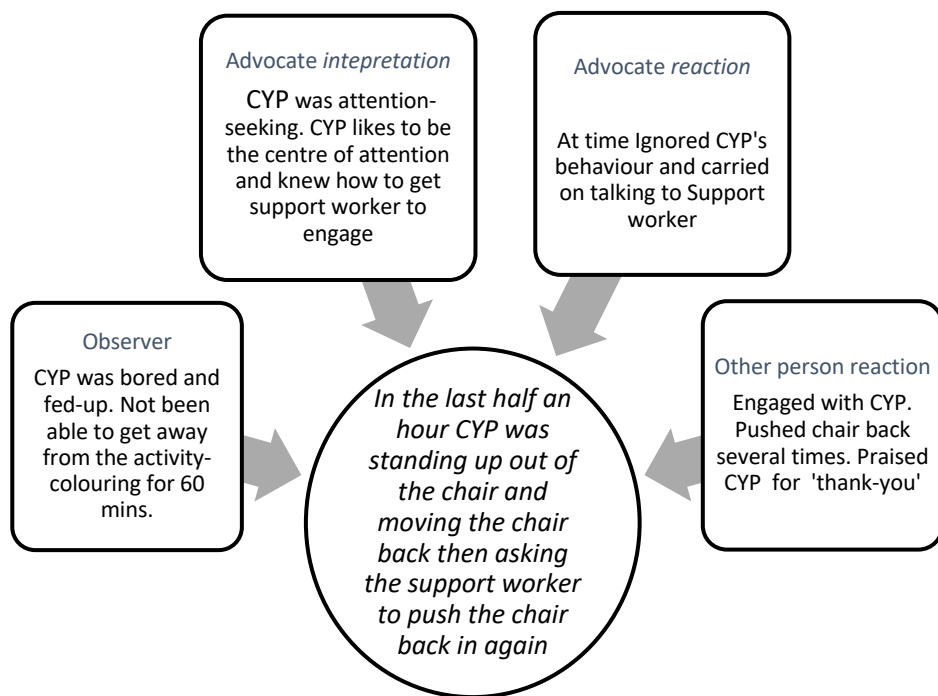


Figure 13 Action and interpretation Example 1

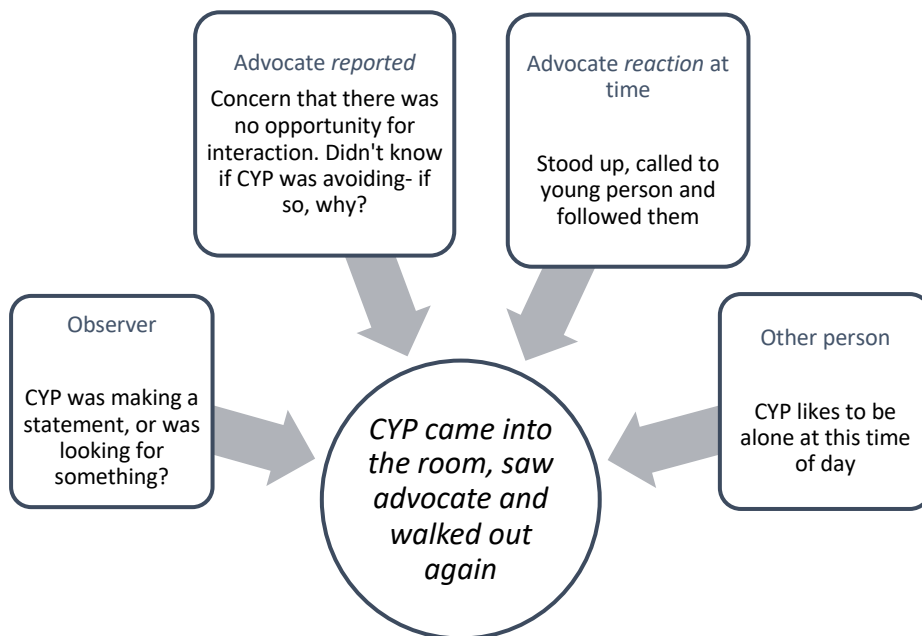


Figure 14 Action and interpretation Example 2

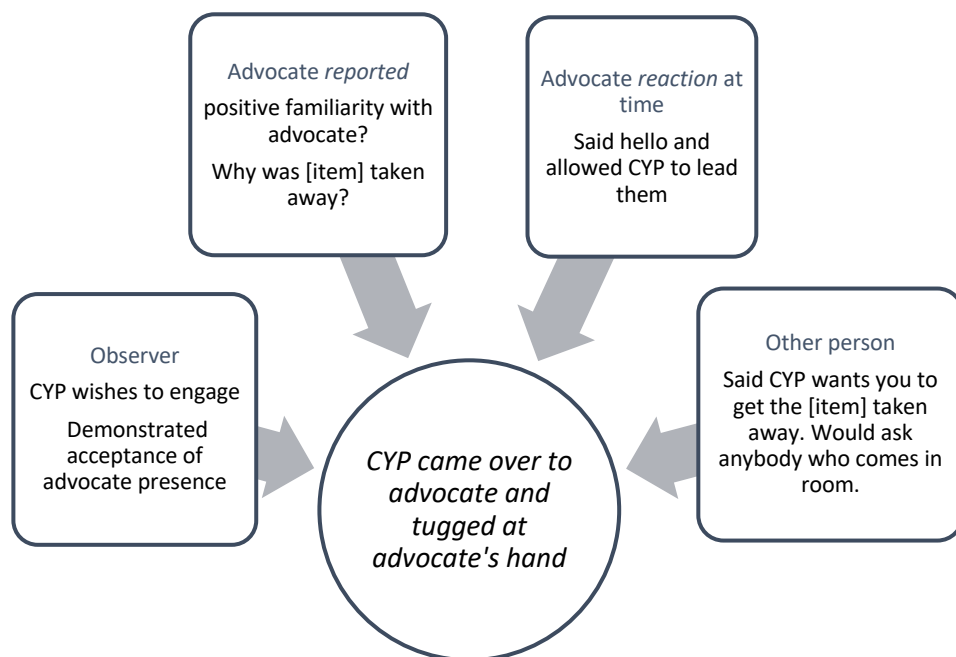


Figure 15 Action and interpretation Example 3

In example 1, the advocate understood the behaviour based on their previous experience of the CYP. I, as an observer, was basing my interpretation on the fact that I know I would have been bored after doing the same activity for a long stretch of time. In example 2, the staff had experience of the CYP and their behaviours given the time of day. This also highlights the importance of understanding *context*. As an observer, I had not enough information to draw a conclusion, but did interpret that CYP did not want to engage at the time. In Example 3, the staff member had knowledge of the events prior to this incident, but both the advocate and I as observer felt that the engagement with the advocate was significant, despite the interpretation of the staff member as to the 'single' intention of the CYP.

Figures 13, 14 and 15 highlight the contentious issues of 'non-instructed' advocacy and 'knowing' the communication intention of a child or young person. Seeking the 'truth' - an accurate portrayal of the child or young person's communication, including their intention, can be interpreted by others differently, and contented

by others. particularly when it comes to decision-making. Nevertheless, adding an outsider; an independent advocate's view of a child or young person's views, wishes and feelings are important to counteract assumptions based on tacit intuition (Phelvin, 2012), and consensus that may need to be re-examined (Greathead et al, 2016; Simmons & Watson, 2010; Petry & Maes, 2006).

Advocate dilemmas around working with others, will further be examined in the following chapter on support. Nevertheless, advocates have a significant role in providing 'space' and 'audience' for a child or young person's expression. Whilst an advocate is not seeking to work in a child or young person's 'best interest', a significant role of an advocate is to uphold the rights of the person they are working with (Brandon & Brandon, 2001; Henderson and Pochin, 2001; Macadam et al, 2013). Therefore, whether or not there is consensus as to the child or young person's meaning of expression, the right to participation should be seen within the context of all the UNCRC articles, and the advocate has a significant role in ensuring that *provision* and *protection* are also afforded to the child or young person.

6.4 Expression; the child or young person as a communicator and the advocate as receiver of communication

Children and young people as communicators have been explored, with detailed descriptions of the 'voice' of the five disabled children or young people with complex communication needs within the live cases. The advocate as an observer of the child or young person's voice has been discussed, with consideration of context, and of interpretation and working with others to

understand intention of the child or young person's expression. This section draws together the child or young person as a communicator, and the advocate as a receiver of communication.

Figure 16 illustrates how the understanding of communication is dependent on a number of factors impressing on the advocate, through training and experience (Greathead et al, 2016; Phelvin 2012), the input from others to aid interpretation of the individual child or young person's communication (Solodiuk, 2013; Petry & Maes, 2006), and their receptivity (Kelly, 2000) to the child or young person means, intent and context of communication. I am conscious that this diagram does not adequately explain the 'dance' of coming to consensus of meaning through 'intensive interaction' (Goodwin, 2013; Caldwell, 2012; Hewitt & Nind, 2010). Yet it acts to demonstrate that understanding expression is a dynamic conceptualisation, and that advocates have to be conscious of the elements thereof.

Issues for the advocate of understanding a child or young person's expression can be divided into two distinct sets. Firstly, issues within the micro of the child or young person/advocate relationship; the use of appropriate communication tools, building up a relationship, the complexities of "knowing". But many of the issues cannot be divorced from the second set of issues; the context - the macro or meso system of the child or young person, (Bunning, 2009) in which advocacy is practised. The agenda of others, the opportunity to spend time with a child and young person with implications for cost for both agency and commissioning services, confidence through training or experience of the advocate, and the complexity of the relationship with other people around the child or young person impact on the advocate's understanding of the individual and their communication and 'space' (Lundy, 2007).

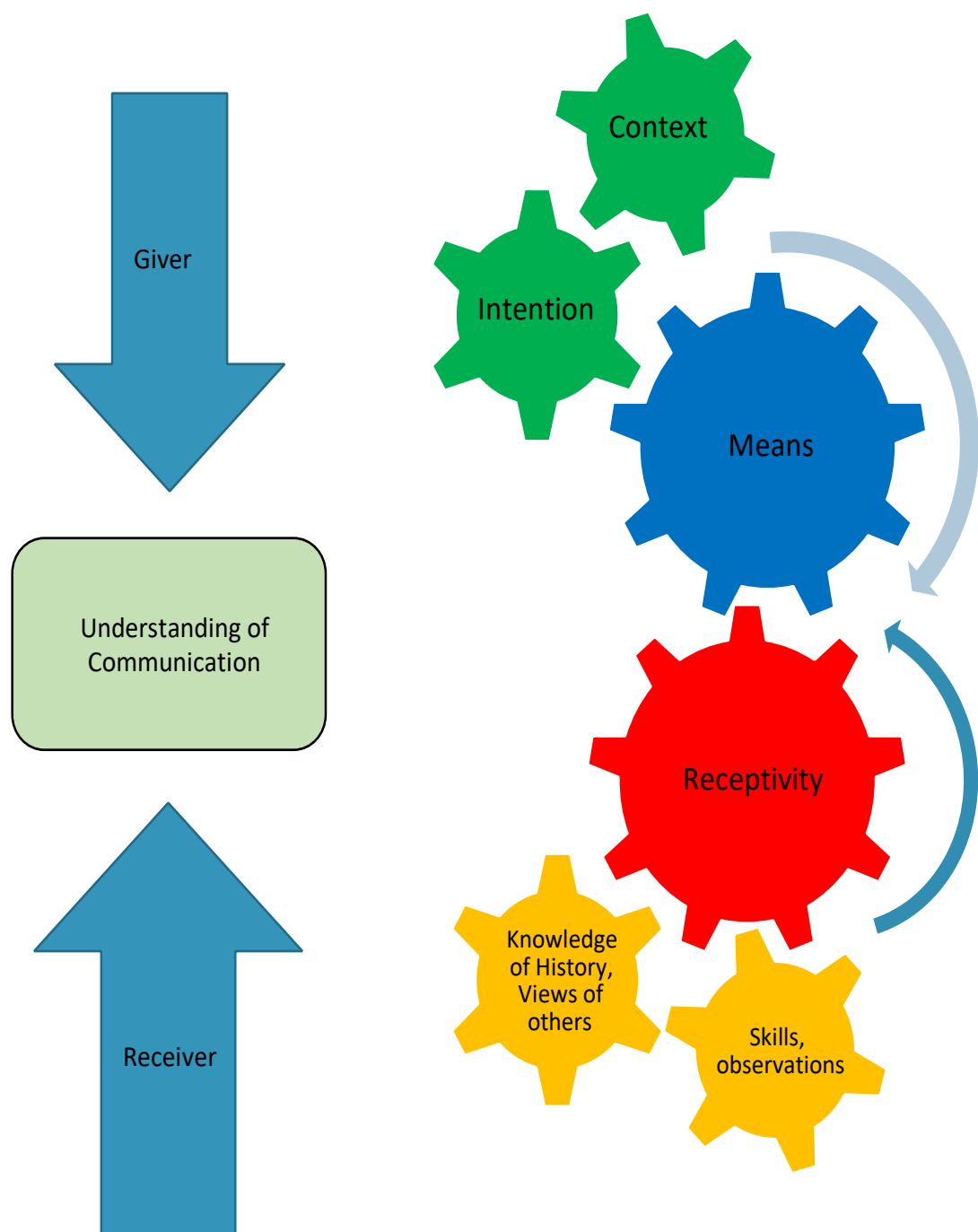


Figure 16 The relationship and influences on communication between the CYP as giver and advocate as receiver

Expression - Concluding Comments

In the five live cases, the researcher's observations largely correlated with the perceptions of the advocates working with these individuals as to the means of communication, but there were variants in the meaning and observation of the context of the communication.

The children and young people communicated in a variety of ways; through gesture (not necessarily makaton or sign-along, but their own individualised gestures interpreted by others over a period of time). These were understood and often acted upon by advocates during their visits. The children and young people also communicated through vocalisations- although not necessarily recognisable words. Vocalisations were non-directional (humming to self), or directional - to express feelings or wants, or to make a response. Some of the children and young people communicated through a variety of facial expressions. Two children or young people were observed to respond or request using symbols, another reportedly used iPad technology. Behaviour as a means of communication was recognised by advocates, as evidenced in their post observation interviews.

In the vignettes, advocates recognised that there were many ways of communicating, including through behaviours, although some advocates did not necessarily pick these clues up from the text without prompting. Where direct verbal communication was perceived to be more problematic (Dylan and Shabnam), advocates asserted that they would use observation to a greater extent, and many claimed they would attempt to use other methods to interact, including play, art as well as recognised AAC such as PECS. There was a range of experience, confidence and skill levels of advocates, and this appeared to

influence how they approached cases and arguably their effective observation and receptivity.

In the live cases, advocates related with others around the young person regarding communication methods and meaning for the individual. This correlates to the evidence from the advocates interviewed responding to the vignettes, indicating that advocates often approach others for information about communication methods for the individual child or young person. In both cases and vignettes, advocates were open to taking direction from others with regard to safety and well-being of the child or young person where necessary. Advocates across the study were aware of their presence potentially influencing the behaviour and well-being of the individual child or young person.

The advocates in the live cases were sensitive to the *means* of communication of the individuals but were also aware of the *context*. Influences of time-of-day, weather and temperature, physical environment, as well as seeing a young person over a period of time and where possible in different settings. Many of these contextual issues effecting the advocacy- child or young person relationship were also cited by the vignette interviewees in examples of practice.

Much of my reporting in this chapter has been focussed on the means, context and intention of communication, yet the *subject* of communication can lead to inferences being drawn as to wishes and feelings, likes and dislikes of the child or young person. For example, Rowan's like of music, Kim's like of animals, Tobi's preference for the company of peers, and the fact that going home mattered a great deal to Eden. The advocate has been an observer of the child or young person's voice. The support for a child or young person expression through the advocate's facilitation of 'space' and 'audience' in child or young person's participation, will now be examined in the following chapter.

Chapter Seven: Support for the voice of children and young people with complex communication needs through advocacy

The child or young person as a communicator, the advocates observation and recognition of the meaning of the 'expression' of a child or young person's communication was the focus of the previous Chapter (chapter four). Consideration was given to the *means*, *context* and *intention* of the communication. How a child or young person expression could be negotiated and comprehended by advocates working alongside people who know the child or young person, was also explored. This chapter focuses on the 'support' for the child or young person's expression through advocacy provision through the giving of 'space' and 'audience' (Lundy, 2007).

This chapter commences with the evidence of 'support' for the child and young person's voice at the micro-level of interaction between the individual child or young person and their advocate within the study. The interaction of the advocate with the meso- level, namely the parents and staff working with the child or young person will then be examined in relation to the opportunities and challenges in working to 'support' a child or young person's expression and participation. 'Support' for the voice of children and young people in terms of advocacy provision, access and legislation within the macro-level will then be considered. Finally, the skills, experience, knowledge and training of the

advocate to support the voice of children and young people will be reflected upon.

The sections of this chapter are as follows:

- 7.1 Support within the child or young person and advocate relationship
- 7.2 Working with others to *support* expression- meso-level
- 7.3 Working with others to support expression: beyond the macro
- 7.4 Advocate training, experience, skills, confidence and knowledge to ‘Support’

7.1 Support within the child or young person and advocate relationship

The role of ‘support’ of advocates in facilitating participation is the focus of this chapter. Both the vignette cases and the ‘live’ cases will be considered, as both offer insight into the advocacy relationship.

I have made a deliberate distinction between the advocates ‘*observations*’ of the child or young person in the previous chapter and incidences of *interactions* between the advocate and child or young person in this chapter. Interactions between the child or young person and the advocate, the giving of ‘space’ and ‘audience’, in order to *support* the ‘voice’ of the child or young person will now be considered through in the analysis of the ‘live cases’.

Direct interaction was attempted by all advocates in the ‘live cases’. However, this ranged from fleeting greetings with Sasha, to verbal interaction with Rowan and Kim, to mirroring response akin to intensive interaction (Goodwin, 2013;

Caldwell, 2012) with Tobi. The extent of use of AAC by the advocate with individual children or young people rested on several factors with the child or young person themselves and the context and intention of the visits. Analysis of support within the live cases will begin with support *through* interaction, then consider support *without* interaction.

Support *through* Interaction in the live cases

Kim

Kim's advocate spoke to Kim directly, although Kim's responses were often through gesture or answered through support staff after Kim looked towards to staff member to answer on Kim's behalf, with Kim demonstrating approval of the answers through gesture. Kim's advocate questioned staff during one visit regarding the issue of Kim's shoes and included Kim in the conversation and watched Kim's reactions. When a potentially upsetting issue was raised by staff concerning Kim, the advocate took note of Kim's 'non-reaction' as significant (see Grove et al, 2000) recognising non-reaction as a means of communicating. Speaking after the advocate explained that although they were keen that Kim was part of the conversation in order that Kim was able to participate, they also questioned whether there was sometimes a case whereby 'support' for a child or young person participation may be detrimental to a child or young person's wellbeing. This is perhaps as demonstration of where an advocate, working in a 'non-instructed' way, can advocate 'for' rather than the ideal of 'with' a child or young person.

Rowan

Rowan was very keen to interact with the advocate and myself. On the first visit, Rowan's advocate directed questions towards Rowan, attempting to elicit Rowan's expression of feelings about the placement. Whilst the advocate waited

for responses, often questions were answered by staff with Rowan's 'voice' having no 'space':

Advocate: [turns towards Rowan] "How do you choose what you have for lunch?"

Rowan [sign for eating] "pie"

Advocate: "Do you get a choice?"

Support Worker: Yes.

The setting itself made supporting Rowan to express their wishes and feelings difficult. After the observation in this setting, I spoke to Rowan's advocate about privacy and opportunities for seeing Rowan in a separate or quiet corner. The advocate responded that they thought that was a possibility but hadn't asked because they didn't think that support workers would let them see Rowan alone. They felt frustrated in the barriers to supporting Rowan's voice and eliciting Rowan's wishes and feelings about that particular setting by the dominance of the support worker present. Whilst the advocate felt that it was not necessarily the presence of a support worker as the issue, rather the support worker's presumption of speaking *for* Rowan and then Rowan's subsequent passivity. When we saw Rowan again, Rowan appeared more relaxed and communicated directly with the advocate. Staff around did not 'jump-in' with responses on Rowan's behalf. The setting was an important factor in the support that was able to be given by the advocate to Rowan's expression. Both 'voice' and 'space' were facilitated.

Tobi

Tobi's advocate aimed to use communication tools that they had established were used by others around Tobi to aid Tobi's communication. On the first visit observed, the advocate had prepared some picture and symbols material, however, the advocate realised that it was not familiar for Tobi and abandoned using them on that occasion. On a further visit, the advocate also observed that it was not clear whether Tobi understood the cards used by others, and that Tobi

was attracted by images of faces or the use of real images rather than symbols. This was confirmed by a carer. Tobi's advocate throughout visits attempted to understand Tobi's communication for themselves. I had noted how the advocate spoke to Tobi and also responded verbally and through gesture to Tobi's actions, whether they were directed at the advocate or not. The advocate themselves also reported how they mirrored Tobi's actions to elicit further response. This is seen clearly in the following interaction recorded using non-verbal communication detailed observation pro-forma.

Tobi: Rolls large ball (1metre diameter)

Advocate: receives the ball, smiles and says "Thank-you Tobi" Rolls the ball back

Tobi: touches ball as it stops near

Advocate: bounces another small (light up) ball. Directs toward Tobi

Tobi: makes a noise- watches ball

Advocate: Sits on floor near Tobi. Moves towards Tobi and runs ball up and down (own) leg. [Talks to Tobi then to TA during this time]

Tobi: sits with legs out facing advocate Hands still. Watches ball.

Two minutes later:

Tobi: lies on floor eyes towards advocate, makes no movement.

Advocate asks "Are you tired Tobi?"

Tobi: picks up stick (attached to toy puzzle with 3 coloured sticks and series of balls)

Advocate: points to stick "What colour is that? It's red..."

Advocate then lies down on mat mirroring shape of Tobi

Tobi: Eye contact and makes small movement with stick towards advocate

Advocate: walks fingers in front of Tobi.

Tobi: Follows fingers with eyes. As fingers move near, Tobi reaches out and links little finger to advocate's little finger

Advocate: Holds little finger whilst talking to Tobi (very softly)

Tobi: Lies still.

(Taken from NV Obs A1.1)

Tobi's advocate felt that their role was to establish a rapport with Tobi. Tobi's advocate observed the changes in Tobi's reactions towards themselves over the duration of the visits, from apparent indifference to acknowledgement, and then to Tobi responding. Receptivity and reciprocal interaction is facilitated through the development of relationship over time (Greathead et al, 2016; Underwood et al, 2014; Wickenden, 2011). Whilst the advocate may have under-played their role in facilitating this change, I felt as an observer, that the considerable receptivity and response to Tobi's means of communication from the start, meant that the advocate was indeed supporting Tobi's participation. The advocate received communication (Nind, Flewitt & Payler, 2010) and acted upon it appropriately (Kelly, 2000).

Eden

Eden's advocate expressed a sense of frustration because they were thwarted in building up a relationship with Eden in order to support Eden's voice because of the timing of the visit. Time and timing were repeated issues for advocates across the study. Whilst having an open mind as an unfamiliar observer of communication can overcome preconceptions and prejudices through overfamiliarity (Lyons, 2003), when considering interaction to *support participation*, time spent to build up a relationship, enables 'space' and 'audience' (Lundy, 2007). Receptivity and reciprocal interaction is facilitated through the development of relationships over time (Greathead et al, 2016; Underwood et al, 2014; Wickenden, 2011).

Support for 'voice' *without* interaction in the live cases

It important to consider how advocates can support the 'voice' of the child or young person without interaction. One of the challenges faced by the advocates for Sasha and for Eden, was Sasha's and Eden's individual communication

challenges around interaction. My observations and initial reflections noted that Eden's advocate appeared to not notice the same non-verbal communication and behaviours that I had observed and noted, regarding Eden's need to be left alone and not wanting to interact with the advocate. Yet in post-observation conversations, the advocate had indeed drawn the same conclusions, but said they were unsure as to the appropriate response at the time, given their remit as an advocate and the limitations of the timing of the visits. Nevertheless, Eden's advocate advocated for Eden around issues of care by asking questions and pointing out rights to the staff and carers. The advocate was in touch with various parties involved with Eden's support and despite their frustration at not being able to build up a relationship with Eden, the advocate was still able to support Eden's rights, particularly rights to provision. In raising the issue of timing of visits to Eden, the advocate possibly facilitated future advocacy support for Eden's right of participation.

Sasha's advocate was aware that Sasha had routines and rituals that the advocate had to be careful not to interrupt as this would cause Sasha to become stressed and anxious. I was briefed prior to my visit as to potential triggers and appropriate responses, not just for my own safety, but for Sasha's wellbeing. On one visit, the advocate after speaking to carers, made the decision with carers, that Sasha was too agitated for our visit to be of benefit and may indeed have been detrimental, in that our presence could trigger behaviours that may harm Sasha or others around. The cause of the agitation was not known and unlikely to have been our visit, but the awareness of behaviours and the concern for Sasha's wellbeing demonstrated a regard for their communication through behaviour (Caldwell, 2012; Grove et al, 2000).

I recorded that on a visit to Sasha, the advocate said hello to Sasha, and Sasha reciprocated by tapping the advocate's hand (Obs C.1) This has been a recent development in the relationship between Sasha and the advocate. The advocate's ongoing sensitive observation and understanding for Sasha's

communication over time were possibly influential in this development. As we were leaving, the advocate:

...indicated that [they] would not interrupt [Sasha's] activity to interact further but call to [Sasha] to say goodbye as we left. Carer acknowledge that that was the best way, as [Sasha] would want to know that Advocate was leaving.

The advocate and I discussed issues of working in a non-instructed way, and that even with the non-instructed advocacy “gold standard” of eliciting wishes and feelings through direct interaction; interacting directly with Sasha needed to be on Sasha’s terms.

After one observation with Tobi, the advocate and I discussed the additional challenges of communicating with children and young people with complex communication needs, and the additional issues of communicating with any child or young person who is not familiar with the advocate in order to build up a relationship. As with Eden’s advocate, Tobi’s advocate saw Tobi’s initial behaviour in context of ‘reaction to stranger’ as well as Tobi’s communication challenges and this is an aspect that has not really been explored. Children, particularly disabled children, have many professionals talking about them, hopefully to them, but nevertheless often coming in, uninvited, to their spaces. A ‘voice’ in participation, is recognised by Lundy (2007) as also being a choice *not* to communicate. Withdrawal in both Eden and Tobi’s cases could be seen as a measure of ‘social agency’.

None of the children or young people in the ‘live’ cases were able to directly ‘instruct’ an advocate (as in ask for an advocate and directly instruct), and so all the advocates were acting as ‘non-instructed’ advocates. Nevertheless, through observation and talking to other people, advocates were able to get a sense of the child or young person’s communication means and intent, and their individual preferences. Developing a relationship through interaction with Tobi,

Kim and Rowan enabled their advocates to build on their understanding of the individual.

Whilst Kim and Rowan were able to indicate preferences themselves through body language, gesture or verbal response directly to the advocate, Tobi was in the process of getting to know their advocate and building that relationship- which may in the future, lead to Tobi being able to directly communicate preferences to their advocate. Sasha and Eden's complex communication and additional needs required the advocates to often work without interaction with Sasha and Eden. The issue with non-instructed advocacy where the child or young person is not interacted with to ascertain (as far as possible) their preferences, is that advocacy becomes more akin to a 'guardian of rights'.

Advocates are sometimes reliant on observation alongside the input of others rather than the direct child or young person/ advocate relationship. Nevertheless, it is the child or young person's behaviours, relationships with others and their surroundings; their actions and reactions which is the child or young person's 'voice'. And therefore, the observations of these by the advocate as an *independent* advocate, is crucial. These observations of the child or young person's 'voice' become the 'support'- the mechanism for the participation of the child or young person in their everyday lives by giving 'space' and 'audience' through the independent advocate. Both Sasha's and Eden's advocate were able to advocate and support the expression of Eden and Sasha's preferences precisely through their observations and their subsequent conversations and reports to others.

Support in the Vignette cases

The vignettes (See Appendix 4) offered opportunity for advocates interviewed to discuss how they would approach and support the individuals; Shabnam, Billy and Dylan.

Dylan

One advocate initially was going to call Dylan and speak to Dylan directly about confidentiality and make an appointment to see him face-to-face. I reminded the advocate that the research was around non-instructed advocacy, and the information did indicate that Dylan had autism and severe learning disabilities: had they considered this in their approach? This advocate acknowledged that they had little experience but stated they would ask other advocates with more experience as to what tools would be best to use with Dylan in advocacy interaction. This advocate recognised that non-instructed advocacy would require many visits in different settings to see how Dylan responded. Conversely, another advocate stated:

‘Obviously when it says its severe learning disabilities, I want to see whether it warranted me visiting Dylan anyway...to see if I could gather anything from him at all’.

When pressed, the advocate went on to question what was meant by severe learning disability and what communication tools, if any Dylan, was using. This advocate had little experience with working with disabled children. The remaining nine advocates responding to the vignette, assumed that they would visit Dylan at some point to establish a relationship with him and to see what was going on in school before the Education, Health and Care (EHC) review meeting. Three stated that they would also ask to see the EHC plan and/or CAMHS reports as this could influence or be useful in understanding Dylan and inform their interactions with Dylan to establish his wishes and feelings. Advocates also felt that the information gleaned from viewing these could also be used to check that Dylan’s rights to provision were being met through the fulfilment of the existing plans.

Billy

Billy presented a slightly different scenario in that the advocate was visiting Billy already. Several advocates were clear that, although their agenda would have been dictated by others regarding transition planning for Billy, and advocacy would be to support her voice in future plans, when presented with Billy that agenda would have to be suspended. (Note that advocates initially assumed Billy was male):

...he is mentioning Trish, so we can kind of deal with that issue because it is clearly important to him. Then look at the areas around his transition plans after that, to make him feel a little bit better and that he can trust me. AV

Three advocates explicitly stated that they would be led by Billy. Almost all advocates said that their priority would be to respect her wishes and feelings and desire to talk about Trish (Billy's sister) and to build up a relationship with Billy:

There would be at that point no point in gaining his views and opinions regarding anything else because that's what's important to him at that time. He needs to be listened to. AM

There was a wide-spread recognition that often an advocate goes into a situation expecting to support the child or young person regarding one issue, but discovers other issues are more pressing in the child or young person's life, either through observing an issue that needs to be addressed, or through interaction with the child or young person. Their role is supporting the child or young person to express their views and feeling and to act as a conduit to other professions around concerning this.

Many advocates talked about their role to support Billy in her understanding of the choices open to her before and after the meeting regarding the future:

It says he's got other options but what are they? He needs to know and to be included in how he feels about what the options are... Kind of go backwards and forwards on Billy's behalf and that can take a long time AV

Advocates were clear that their role was not to act in the 'best interest' of Billy, but to support her voice to be heard; to have both space and audience:

it's about what Billy wants to say and what Billy wants to put forward... I am purely stating what Billy would like to happen. If that can't happen, why not, and when will it be resolved? AZ

Regarding the issues of previous domestic violence in Billy's life, some advocates spoke of the 'skirting over the issues' by some professionals because they are afraid or do not know how to communicate with the child or young person regarding difficult subjects:

Sometimes somebody is compromised in the way that they communicate, that is a really specialist area and some professionals can be reluctant to approach the subject because they feel it might upset the person, they question how a person might cope with it, and feel they can gloss over it. AM

Support offered by the advocate can be three-fold; firstly, by challenging professionals to explain in terms the child or young person understands. Secondly, to support the child or young person to access appropriate resources- 'provision' to develop coping strategies and address their feelings. Thirdly, by supporting the child or young person to understand and process alongside other professionals. As Kennan, Brady & Forkan (2017), Macdonald (2017) and Cossar et al (2013) found, children and young people's voices are often overlooked in areas of domestic violence and abuse. Some advocates rightly questioned the label of Billy as a 'perpetrator' of domestic violence. Nevertheless, not addressing the issues where the rights of the child or young person or others are violated, can be counterproductive and lead to further abuses (Swift, Waites &

Goodman, 2018; Smeaton & Franklin, 2016). Billy not being supported to understand the family situation and why she was in care, was possibly a barrier for her rights of participation and rights of protection.

The Billy vignette also enabled exploration with advocates as to how they would deal with challenging behaviours and the advocate's subsequent approach to continuing support. Supporting Billy to express her feelings or concerns around her sister's boyfriend was acknowledged as important by most advocates, whether this would be immediately, or after a calming down period. Several advocates recognised that this might be a situation that needed to be passed on to other people because it may be a safeguarding concern. This will be discussed further in chapter eight (Regard), concerning the recognition of Billy's expression, giving it 'space' and 'audience' and 'influence'.

Shabnam

Three advocates questioned whether this case would be passed to them because of the mum's reported reluctance to engage and consent. Whilst some advocates were concerned about the issue of mum's apparent reluctance to engage and 'allow' Shabnam to see the advocate and saw mum as a potential barrier to support, they all eventually came to the conclusion that to speak to Shabnam herself would be preferable. Only one advocate queried Shabnam's medical condition and said they would 'Google' it to find out more. They wondered whether this would impact on Shabnam's communication. After part two introduced the fact that Shabnam's mother had language barriers, some advocates suggested that Shabnam herself may not have English as a first language and contemplated barriers to expression and how these may be overcome through the use of a translator.

Many advocates recognised their role in supporting Shabnam's voice concerning her respite provision, although several advocates appeared to be deferring to

mum rather than establishing a relationship with Shabnam herself to support Shabnam's voice directly. This may be to do with advocates confidence in communication and/or uncertainty as to the cognitive abilities of Shabnam.

Some advocates saw a duty to raise the issue of the high turnover of social workers with social work management as part of their role. Again, whether this was based on the assumption that Shabnam herself indicated that this might be an issue, or mum, or in fact, the advocates own perceptions of the benefits of consistency with social workers was not explicitly explained by the advocates:

A lot of young people I work with who have complex difficulties have many changes of social workers. Sometimes we can be the only consistent professional working with that person. I don't think that young people should just accept that. I want to challenge that as to why her social worker has been changing so much and to try and get some continuity. AW

Several advocates echo that building up a relationship with themselves as an advocate, and supporting the child or young person to also have a relationship with professionals making decisions about the young person's life, enables the communication *means* and *intent* of the child or young person to be better understood by others. Therefore their 'voice' has 'space' and 'audience' (Lundy, 2007). One advocate spoke at length of challenging consistency of care workers for a child or young person they were supporting for this very reason. Therefore, advocates questioning the consistency of other professionals around the child or young person can be viewed as supporting the child or young person to participate through being 'known' by decision-makers.

7.2 Working with others to *support* expression- meso-level

As illustrated in the previous point, the role of an advocate extends to beyond the micro-level of the advocate/child or young person relationship. This next section considers the role of others with whom the advocate interacts in meso-level of the child or young person's ecosystem, in together supporting the child or young person's expression or 'voice'.

The role of parents

The observation of all the live cases- residential and non-residential were facilitated by the consent of parents. Although attempts were made by advocacy agencies to facilitate my observations of children and young people with Care Orders, there was a reluctance to give permissions by other professionals or foster carers. This is something that I understood and appreciated from the point of view of 'Best Interests' decision-making processes.

Whilst direct observation of face-to-face interaction between parent and advocate was only possible for one child or young person, all advocates in the live cases involved and consulted with parent(s) at some stage during the advocacy process. The vignettes reflected the diversity of parental involvement; Dylan's parents had asked for advocacy support, whilst Shabnam's mother initially appeared to be reluctant to engage. Billy was under a Care Order but had some contact with family (sister). The issues surrounding relationships with parents was discussed with advocates and some advocates offered examples of interactions with parents to highlight challenges and opportunities when working with parents and families of children and young people in supporting the child or young person's own voice and/or issues of parent's support needs.

In addition to the data gleaned from the 'live' cases and vignettes, four parents provided feedback regarding advocacy (although not all their children were amongst the five final cases in the fieldwork observations). This data from the parent's feedback enables insight from the parent's perspective of advocacy thus giving a 360° view of the interaction between advocate and parent and the support offered by the advocate to the child or young person.

The interaction of advocate and parent at the **referral stage** depends on the circumstances of the referral, and the service provided. For the children and young people of the live cases in residential settings, an advocacy service was provided on a once a month or once a fortnight basis. Whilst parents were told about the service, the interaction between advocate and parent varied. One of the parents giving feedback about a residential advocacy service felt that their child's appointed advocate could have contacted them as parents for more information. Whilst they understood that the service was for their child or young person, they felt that they could have aided in the advocate's understanding of their child's specific needs and communication methods. It could be understood that the parents felt consultation would aid the *support* given by the advocate in facilitating the voice of their child by a deeper knowledge and understanding of their child's '*expression*'.

In the 'live' cases, parents for the two issue-based non-residential cases, had referred to advocacy services on behalf of their child for upcoming reviews and potential issues around future planning and resourcing. They believed that advocacy was important to *support* their child's right of *expression*. In essence, they had supported their child's voice by referring to independent advocacy. For one family, the referral for their child was made because of conflict of opinion between themselves as parents and professionals involved in their child's care. Another parent felt that their child should have an 'independent person', contrary to professionals around the child who had assumed that the parent would be the appropriate 'advocate'. This parent saw that having an independent advocate was a means for their child to have a relationship with

somebody who could get to know them beyond the superficial- in order that their child could communicate meaningfully and have their views considered by decision-makers. This parent was active in promoting advocacy to other parents.

In the vignettes, Shabnam's case highlighted advocate's approach to parents as 'gatekeepers' (placing barriers to participation by delaying, blocking or non-cooperation with the support offered by independent advocacy). Some advocates appeared to question the mother's rights to refuse advocacy, whilst others, the rights of Shabnam as a sixteen-year-old to advocacy. This may be through the advocates lack of understanding or knowledge of legislation surrounding rights of parents and/or young people aged 16 or over, or limitations of experience, or indeed the remit of the advocacy service from which the advocate came¹⁷. Despite discrepancies, most advocates agreed that they would attempt to communicate directly with Shabnam's mum as gatekeeper, to reassure or appeal regarding access to Shabnam herself in order to offer *support* for Shabnam's voice in the form of independent advocacy:

I would try and speak to mum and explain exactly what our role is and what we do. As we find in most new referrals that we get, we find that most parents and the children don't know what an advocate does, what our role is and what we do, what we can support and what we can't. AJ

But it is helpful to have them on board...It would be a case of making sure that in the initial contact with mum, we made it very clear what our role is. Promoting the role as to how it can help Shabnam. Although the issue of support¹⁸ has been raised, it might be mum's issue, not Shabnam's. I would ask mum what support is being offered and try and go from there really. AL

With Dylan, advocates did not question the description of Dylan himself by the referring parents. However, many warned of the issues of being led by parents when the advocate relationship should be with child or young person:

¹⁷ it should be noted that some advocates worked in services that provided advocacy only for children *in care* under the remit of their commissioned advocacy service. This must be considered when analysing advocate approach to parents or unpaid carers and their families.

¹⁸ Support here refers to provision- not support for participation.

It could be seen as taking on the parents' issues not Dylan's issues, and therefore need to be really clear to parents that I wasn't there to kind of put forward their wishes and feelings....it will be very much around Dylan. AY

The *support* for the child or young person should be to facilitate the *expression* of the child or young person, not to be a mouthpiece for the wishes and feeling of the parents:

It can be overwhelming and there are so many battles to fight on the way when you have a child with disabilities. It can be exhausting and frustrating for parents. Whilst you listen to them, you have to keep come back to 'what is my role?' AL

Nevertheless, it was acknowledged by advocates that the parent-voice contributes to raising issues of provision in particular for disabled children and young people. This was confirmed by the parents themselves, with three of the parents in the study speaking passionately of the continual battle for resources and funding for their child and of their appreciation for the support of advocates when dealing with health, education and social care. The findings of this study confirm evidence of numerous other studies (Krueger et al, 2019; Adams et al, 2017; Longfield, 2017; Wynd, 2015; Michell, 2012a; Brady, 2011; McGrath, 2010; Burke & Goldman, 2017). Advocates were mindful of the parental backing of the support that they, as advocates, could offer and the parental contribution to understanding of communication means and intent. Parents were also recognised for raising issues for the advocate to observe and consider in their support of the child or young person voice. Whilst advocates for the 'live' cases did not raise the issue of parents being a hinderance, this was raised by some advocates in interviews. It was suggested that perhaps parents, like other professions, may not be aware of the unique role of independent advocates to support their child's voice.

In all the live cases, the advocates demonstrated that they were aware of the need to communicate and have a positive relationship with parents and the family of the child or young person they were advocating for/with in order to gather information. The degree of interaction with parents differed, but this could be related to the circumstances and age of the child or young person and whether they were seen as part of the residential advocacy service, or issue-based case advocacy, and therefore no conclusions can be drawn from this variance. In the live cases, I observed that advocates had a genuine regard for the parents' experience and knowledge of their offspring and were careful to maintain positive dialogue, whatever the degree of this interaction was, depending on the circumstances. Nevertheless, as indicated in Chapter five and six, advocates have to hold in one hand the views of parents and professions which brings longevity and depth of working or living alongside, and on the other hand the convictions of their own observations which may reveal other truths and insights to support the child or young person in their expression of their wishes and feelings.

The role of others in referral

Whilst parents are known to refer for advocacy, other professionals working around the child or young person are often in a position to, and indeed obliged by legislation and guidelines to refer (issue-based advocacy). The relationship of the advocate with others within the ecosystem of the child or young person- the meso-level, is therefore important to consider. Social workers should be aware of independent advocacy- it is written in the *Professional Capabilities Framework* section 4 (HCPC, 2012).

Specifically relating to disabled children or young people with complex communication needs, many advocates identified that other professionals were either unaware of 'Non-Instructed' advocacy, or did not understand the specific role:

Professionals don't always know the role of advocate. AZ

Social workers on the phone then saying- "I have been told" [to refer to advocacy] ...there is still not enough awareness of what the benefits are. AJ

social workers don't know or don't think about advocacy. AP

(An issue is) social care taking you seriously- can be very difficult as they don't always understand non-instructed advocacy. AW

Some advocates reported that their local authorities were good at disseminating information about advocacy to social workers in particular. This was perceived by the advocates working in these areas to have had a significant impact in the number of referrals, particularly for non-instructed advocacy. Another advocate reported that a particular IRO in their Local Authority was very good at prompting social workers to refer for Independent Advocacy.

Where advocacy referrals were inconsistent for disabled children and young people, particularly for non-instructed advocacy, advocates identified that often referrals were only made with the underlying reason of actual conflict:

If there is an issue, or conflict between different people-that is when a referral will come through, as opposed to an automatic Care Act transition referral...we should get them through automatically, but that tends not to happen. AM

The reason for late referrals were not specifically identified, nor the reasons for 'non-automatic' referrals under the Care Act. It should be noted that Care Act is mostly applicable to young people, particularly going through transition planning, and some children's advocacy services would only be involved in cases where they had worked with a child or young person before the age of sixteen or eighteen. New referrals would go to adult services. Yet, one adult advocate said:

'The fact that my experience is limited makes me think that [referral rates are] not very good'.

This was despite a dedicated Transition Pathway social care team in the Local Authority.

EHC plans are highly relevant for disabled children and young people. Whilst a couple of advocates stated that there was automatic eligibility for referral in their particular Local Authority (LA), there did not appear to be the assumption by advocates that advocacy referrals should be routinely made for a child or young person with an EHC plan, despite provision within the guidelines for independent advocacy to be available. Referral to, and status of, independent advocacy does not appear to be consistent across Local Authorities. This tallies with findings in commissioner reports (Longfield, 2019; Atkinson in 2014 and in 2016).

Issues of referral, whether this be through lack of information about independent advocacy for professionals, or financial constraints on local authorities for what is known to be more costly advocacy (Griesbach et al, 2012; MaGrath, 2010), directly impacts on the support for the child or young person's voice. Article 12 of UNCRC in respect to 'support' being given to the 'expression' is not dependent on the age and maturity and by inference the capacity of the child or young person. Disabled children are being discriminated against, particularly disabled children with complex communication needs requiring non-instructed advocacy. The value of their voice appears to be diminished, yet whether a child or young person can instruct or not, the right to *support* for 'voice' and the opportunity for 'space' and 'audience' (Lundy, 2007) in order to express wishes and feelings is assured under the UNCRC.

Challenges to support 'voice' in the micro and meso

Some of the difficulties of working with other people in order to 'support' the voice of the child or young person have already been alluded to. Several issues impact on the advocacy relationship itself.

Gatekeeping

Whilst I do not consider this to be the case for Sasha, it must be recognised that not allowing an advocate access to a child or young person (in non-instructed advocacy cases where a child or young person cannot instruct and tell the advocate to 'go-away'), or a child or young person from accessing their advocate may be a sign of a safeguarding issue. The Medway serious case review (Walters, 2019) exposed all too starkly that staff effectively block advocates seeing a child or young person on spurious grounds to cover inadequacies of care and to cover-up safeguarding issues.

Gatekeeping by parents, foster parents or carers in avoiding or placing barriers to contact with advocacy agencies after referral was recognised by many of the advocates. But the advocates were also only aware of the cases after the referral stage, and as highlighted by Longfield (2019) the percentage of children and young people eligible for advocacy and actually currently accessing advocacy is very small. Gatekeeping to voice, space and audience for the child or young person in the support of the advocate may also take a more subtle form; the support worker for Rowan, not giving time and space to develop a relationship with Rowan was in effect taking the role of gatekeeping, whether intentional or not. The challenge for advocates is the management of relationships in the meso system; to give 'audience' and 'space' to develop a micro-relationship with the child or young person. Thereby, the child or young person's 'voice' is understood by the advocate, who can then to act as a conduit and facilitator to that voice.

Understanding communication and capacity

The evidence from across the study indicates that advocates appeared to be aware that referral information can be incomplete or the issues for the child or young person could be different to that initially referred for, particularly in relation to 'issued-based' advocacy. Nevertheless, despite the description of Billy stating clearly that she had limited communication and a learning disability, the

majority of advocates did not question *capacity* and Billy's understanding of words because she had *some* verbal communication. Yet this may be important to consider (Hannon & Clift, 2013; DeVito, O'Rourke, & O'Neill, 2000). Contrariwise, advocates approach to communication and support for Shabnam was significantly different to their approach to Billy as Shabnam was non-verbal, yet there was no indication that Shabnam's capacity was significantly less than Billy's.

Whilst this partly could be explained by the methodological issues of using vignettes in that the advocates had to use imagination rather than be faced with a real person, there may be underlying issues of *expectations* of Shabnam's capacity as a disabled non-verbal young person (Underwood et al, 2015; McNeily, McDonald & Kelly, 2015; Nind, Flewitt & Payler, 2010; Mitchell et al, 2009). It is possible that some advocates were acting as gatekeepers themselves to effective support for Shabnam. This highlights the issue of training for advocates, and reflexive practice to address unconscious bias (Bunbury 2019), and ableism (Pluquailec, 2018; Greatwood et al, 2016) as advocates.

"Non-verbal" does not mean reduced capacity, and being verbal does not indicate capacity, and this is a fundamental issue for advocates to be able to grasp. Interestingly, advocates who had had adult advocacy training or who had had Mental Capacity Act training in previous occupations appeared to be more aware of this phenomenon. For both Shabnam and Billy, it is possible that the support that an advocate could give could be reduced in effectiveness because of their initial perceptions of capacity, rather than their taking the referral and reserving judgement until after information gathering, meeting and getting to know them as individual communicators.

It is clear that some of the advocates lacked the experience and/or training in their approach and support of Dylan and Shabnam as non-verbal communicators. Yet advocates were willing to ask for peer support. A

consideration for advocacy agencies might be the appropriate assignment of cases based on skill sets of individual advocates, and the monitoring of referrals where advocates felt incompetent or under-skilled to support effectively the expression of the child or young person.

Communication tools

For some of the children and young people, the fact they were seen in different settings and at different times, revealed inconsistencies with the use of communication tools. Tobi's advocate had been aware of the use of PECs with Tobi prior to the first visit observed. During that first visit, the advocate noted that the setting was not using the same symbols as used elsewhere and made note to request consistency. Rowan's advocate had worked with Rowan in the past and knew of Rowan's current use of an iPad, PECs and signing by speaking to others prior to conducting the visit. However, during the course of the visit to the first setting, the advocate observed the apparent lack of use of Rowan's iPad and challenged the staff:

...asked about visual prompts and routine for Rowan. Support worker said this was not happening at the moment. Advocate also asked about the use of signing. Support worker prompted Rowan there and then but said that there have been no written targets around their signing.

The advocate was concerned because the issues were not just about Rowan knowing what was going to happen, but Rowan was also not being supported to express their wishes. Without the continued use of the iPad and signing, Rowan's skills were not being utilised, and regard for Rowan's voice was reduced in this setting at this time.

Consistency of communication methods was an issue flagged up by both advocates in the live cases and interviewed advocates. Several examples given in interviews highlighted incidences where children and young people were using

certain communication tools in school, but then these tools were not being used in the home or residential setting. In discussions with the advocates, there was a recognition that parents have been a constant within the child's life, and therefore may have developed their own way of understanding the child or young person without the use of 'new tools' introduced by professionals. In the home environment the 'non-use' of communication tools could be a result of this parent-child relationship or possibly a choice by the child or young person to not 'work' whilst at the home, as this was a place of rest. Nevertheless, the use of communication tools not being implemented in the correct way in settings *outside the home* were still seen as a large issue for advocates with potential implications for the child or young person's participation. If they have not the tools to communicate, how can the child or young person express in a recognised way, are then expectations lowered? Advocates questioned whether this was through lack of staff training, or in fact apathy on behalf of staff.

Several advocates felt that an important role of an advocate when working in non-instructed advocacy cases, was to check consistency of communication, and where there were inconsistencies to try and challenge this on the basis that it was detrimental to the child or young person's right to participation:

A challenge to non-instructed advocacy is overcoming the barriers of communication. It opens up the discussion about how to communicate. Try to get everybody together to develop a consistent way of communication for that person. Money could be a stumbling block as far as resourcing for communication tools.
AM

Collaborative working to understand and use consistent communication with the individual involves the meso- level, but as AM suggests, funding for resources maybe influenced from beyond the meso to the Local Authority as a funding body. Ultimately, financial resources for local authorities is a result of political decisions made by those elected by the general public.

Communication is not the only issue

The advocates who had substantial experience advocating with disabled children and young people with complex communication needs spoke about the multiplicity of needs. As one advocate stated, “communication is not the only issue”. Participation was seen as a core right to be upheld by advocacy working, but advocates were acutely aware that their role as ‘non-instructed’ advocates was wider, by virtue of the fact that the child or young person was not able to instruct:

It is a form of advocacy that we use as a last resort where the young person is not able to give their views, wishes or feelings in any format not just verbally. You still are talking to them, not just about them ...making sure that their rights are upheld. Ask questions on their behalf as well.

It's for young people or adults who are unable to directly instruct you to do advocacy, so it's about making sure that all their rights are protected, and it is a way of making sure their voices are heard as well

Promoting the voice of the child that might not be always be a verbal voice. It's about making sure their rights are respected and they are listened to.

Support for the child or young person’s participation, should be seen in context of the child or young person’s ecosystem (Bunning, 2009). Disabled children and young people with complex communication needs accessing advocacy services are no different to non-disabled children and young people in terms of rights (Pluquailec, 2018; Browne & Millar, 2016), nor in terms of complexity of family, and the education, health and community support around them (although there are differences in resourcing which is discriminatory – Longfield, 2017). Disabled children and young people have a multiplicity of issues in their lives (Davey, Imms & Fossey, 2015; Cohen, 2013; Wood & Selwyn, 2013; Saaltink et al, 2012; Franklin & Knight, 2011) and the vignettes of Shabnam, Billy and Dylan reflected this reality. Billy was in care and had family issues that were priorities for her. Dylan's

family were in conflict with schooling and resources. Shabnam's health care and respite provision was impacting on, and impacted by, family and language issues.

For advocates acting in a 'non-instructed' role, support was seen as not just supporting 'voice', and the rights of participation through the giving of 'space and 'audience'. The role of the advocate extends to ensuring the rights of *provision* and *protection* through their reporting using the watching brief or rights-based advocacy framework. Rights of provision of education, equipment, speech and language therapy; rights of protection from discrimination, from harm or neglect by individuals or institutions were also features of advocacy practice highlighted by advocates.

7.3 Working with others to support expression: beyond the exo-level

As indicated above, access to, and availability of, independent advocacy, particularly specialist advocacy with disabled children and young people and non-instructed advocacy, is also subject to commissioning of services and the capacity of advocacy agencies. The issues within the meso-level are impacted by the decisions and implementation of services from the macro-level.

Commissioning by Local Authorities

Four separate advocacy organisations were represented, yet within an organisation, there were different constraints depending on remits of the contracts with the Local Authority or setting that commissioned the particular advocacy service. This meant that whilst one agency may be able to take referrals from parents under a contract in one Local Authority, the same agency could only

take referrals for Looked after Children under contract with another Local Authority.

An advocate that worked within a service that routinely took referrals from parents in the Local Authority stated that the advocacy service had to turn referrals down- and make decisions on the basis of perceived need. Whether this was because of lack of advocate time, funding, or adequate skill set was unclear from the comments made. Nevertheless, it is evident that when the service is provided for open referral-including from parents, access to independent advocacy is in demand. From this study, it is not possible to determine the path parents and professionals other than social workers can take if they wish to access independent advocacy in areas where there is not 'open'-referral. However, if the child or young person is in residential care, advocacy provision in the form of 'visiting advocacy' may be provided for the child or young person, commissioned by the setting itself.

Visiting and Issue-based advocacy services

Whilst this study did not set out to comprehensively examine the differences between visiting and case advocacy, several issues emerge from the data pertinent to consider in the context of 'support' for children and young people's voice. In 'issue-based' advocacy, advocates attempted to visit a child or young person in different settings and as frequently as possible. Advocates most often referred to the amount of time to give support to a child or young person, in case advocacy:

You can't do that one visit. It doesn't work that way. Takes a lot of time, but it is definitely worth it because they have a right to an advocate, we do just have to give it more work and time. AL

In 'visiting' advocacy, of the live and reported cases, visits were restricted to a certain time and certain frequency determined by the commissioning service-

the setting itself. Advocates were most likely not able to see a child or young person in a different setting. The inflexibility of *timing* was certainly an issue for one CYP within live cases- where the advocate visit was scheduled immediately after school when the CYP wanted to have 'down-time'.

The *amount* of quality time allowed for each visit was reported to be a concern by other advocates too:

I like the idea of an advocate being at these units, but ...really difficult to do because of the limited time they are allowed to spend with the residents. AK

Other advocates thought that the benefit of visiting advocacy was that they were able to get to know a child or young person over a period of time and pick up on issues:

Visiting is useful- sometimes you get rogue staff, so its useful to talk to management sometimes about food, children not getting out enough, equipment not being fixed- that you may not notice if you just doing community advocacy. AP ref2

Yet the *frequency* of visits was a concern noted by advocates within visiting advocacy services, particularly but not exclusively, where a child or young person had encountered an incident in-between monthly visits that may have warranted advocacy with the child or young person. Often events/incidences would be made known to the advocate weeks after, with no contact made by the commissioning body- i.e. the setting for the child or young person. This situation was particularly noted for two of the 'live-case' CYP, but also cited by other advocates as an issue for negotiation with settings. A consideration not overtly identified by advocates, but alluded to, was the issue of funding of advocacy services in residential settings and the continued cutting of funding as a whole impacting on the services schools and other settings were able to buy into- including visiting advocacy.

Boundaries of Commissioning Services

It appears from the reports of advocates across the study, that one of the difficulties of visiting advocacy is the boundary between commissioning service and the rights of the young person to have advocacy beyond those boundaries:

We can advocate for immediate concerns, but more complex issues require negotiation through management with the local authority. AK

For example, several cases were cited by advocates where their visiting advocacy service was not able to contribute to transition planning, advocacy around safeguarding or in relation to DOLs of the children and young people they saw regularly. One advocate was aware that some of the children and young people for whom they were advocating for, were the subject of a safeguarding enquiry by the local authority but the advocate was not involved or informed directly, because the service was commissioned by the setting, not the LA. The child or young person's local authority was responsible for the advocacy provision within these processes rather than the setting in which they were resident. In conversation with advocates, they recognised the distinctions between IMHA or IMCA qualifications and purpose, but often felt frustrated because a specialist advocate would come and see the child or young person once, then write a report that didn't adequately reflect, in their opinion, the child or young person's voice, because little 'space' was given. In some cases, the child or young person would not be represented or supported to participate in proceedings because no advocate provision was made by the child or young person's funding local authority. This must be challenged for future advocacy provision practice.

Many advocates reported that funding LA's were often many miles away from the LA in which a child or young person was resident. This was of particular concern in the communication between LA's regarding safeguarding:

Sometimes we have to go to different local authorities, because somebody is placed out of area. It is the local safeguarding team that will investigate concerns. (Residential rather than paying) Some local authorities are not so responsive, and sometimes dismissive. Even when we know it would have been investigated in this area. For us this is a real concern. As an advocate if you feel that if you're going to a professional body and flagging up a concern and they're not taking it up, it raises more questions than answers. AM

This must be addressed by local authorities. Despite the Flynn report after Winterbourne View (Gloucester SCR, 2012) indicating that children, young people and adults placed in institutions out of area are at increased vulnerability, the fact that advocates are raising this once again, is of serious concern. Advocates are trying to support the child or young person voice, and their rights to protection, but the child or young person is not being regarded. This will be further discussed in chapter eight (Regard).

7.4 Advocate training, experience, skills, confidence and knowledge to 'support'

The role of advocates in supporting the voice of children and young people within the micro-level of the advocate/child or young person relationship through interaction with the child or young person has been considered. The role of advocates as *observer*, *facilitator* and as a *conduit* within the meso and macro-level for the child or young person's expression has also been addressed. Attention will now turn to the advocate themselves. The confidence, experience, training and skills of the advocate are important to consider because advocates *themselves* raised these as issues for their effective support of children and young people voice, particularly for disabled children and young people with complex communication needs. This is also particularly poignant as advocate

capability has been raised once again by the Children's Commissioner in relation to disabled children's advocacy and specifically non-instructed advocacy (Longfield, 2019).

The experience and skills, knowledge and training of advocates will be considered before exploring the place of reflection and supervision in advocacy practice in order to sustain the advocate in supporting the child or young person's 'voice'.

Experience and Skills

Of the 'live case' advocates, three of the advocates had several years of experience as advocates and significant experience as non-instructed advocates. Two had previous experience working with disabled people prior to their advocacy post. One advocate was new to advocacy, although had life-experience of working with children and young people. This individual expressed their concern at their lack of experience with disabled children and young people and that they were not sure as to the amount of interaction they should initiate with their CYP. This advocate felt that they needed more training. Nevertheless, their practice did not necessarily reflect this in terms of appropriateness of interaction and the support they gave for that CYP's expression was not unsubstantial.

In all the 'live cases' no direct correlation between the effective use of AAC and advocate experience could or should be drawn. Nevertheless, many advocates that were interviewed felt their communication skills and understanding specifically with children and young people accessing their services for 'non-instructed' advocacy, was limited and felt they needed more training:

I'm not sure how much I could communicate with Shabnam because of my limited experience (AT).

Whilst the remit of this thesis is not to comment on the practice of advocates, there was a strong correlation between experience of working with disabled children and young people in other contexts and the skill level and confidence of the advocate demonstrated in their reactions to the vignettes, particularly in relation to picking up on non-verbal communication. Advocates with limited experience of non-instructed advocacy and little prior experience of disability in general, gave shorter and less comprehensive answers, particularly for Shabnam and Dylan. It is clear that some of the advocates lacked the experience and/or training in their approach and support of Dylan and Shabnam as non-verbal communicators:

It is difficult to ask him his wishes and feelings as you would for a normal [pause] for a person without disabilities sorry, like that you would have a conversation with. You would struggle to have that level of conversation with a young person (Advocate with limited experience and no training).

This quote does concern me as to the image of disability, normality and expectations of communication the advocate has, possibly due to ignorance. However, it does translate in practice to a 'de-valuing' of that child or young person's voice.

Knowledge and Training

When asked about use of recognised non-instructed advocacy methods, such as 'Watching Brief', a small number appeared to not have had specific non-instructed advocacy training:

No, there's not much demand on my team for disabled children's advocacy, but I am looking forward to gaining confidence and there is a training webinar coming up. AV

Several advocates had completed a two-day training in children's advocacy where non-instructed advocacy was part of the course. Specific non-instructed

advocacy training ranged from two or three days of in-house training to a webinar, or in the case of three of the advocates, no specific training but ‘on-the-job’ encounters. One advocate said that their two-day training “covered everything they needed to know”, but only a small percentage of the course was dedicated to non-instructed advocacy. Several advocates had completed a national Vocational Qualification NVQ level 3 in advocacy (general). A small number of the advocates had undertaken training in Mental Capacity, Deprivation of Liberty Safeguarding, and Care Act training with the emphasis on advocating for people with reduced capacity, and non-instructed advocacy.

In the interviews, there was a correlation between experience and more thorough training of advocates in their referencing of legislation and policy *without prompt* when asked about their plans to approach a vignette case. When pressed about what legislation was applicable, most were able to direct to Human Rights or UNCRC conventions, but a small but significant number did not/ could not cite any other conventions nor legislation. Whilst it should be borne in mind that the sample group was small, all advocates should have been aware of The Children’s Act (1989), UNCRPD, Mental Capacity Act (applied to 16+) legislation, Transition Planning under the Care Act 2014 and Children and Family Act 2014, as all services catered up to at least age eighteen.

Conclusions based on the evidence of training and on-going support to update and apply developments in policy and legislation on an organisational level within this study are limited, but should be considered for further study, in collaboration with advocacy agencies if possible. A consideration for advocacy agencies might be the appropriate assignment of cases based on skill sets of individual advocates, and the monitoring of referrals where advocates felt incompetent and under-skilled to support effectively the expression of the child or young person. Appropriate and timely training to enable advocates to feel confident to recognise, and be receptive to, subtleties of communication.

Supervision and Reflection

In the interviews, many advocates spoke of their use of supervision to discuss how to deal with the issues of dignity and confidentiality raised in the Shabnam vignette. Almost all advocates suggested that they would talk to their line managers to discuss or pass on Billy's reactions and potential issues of safeguarding. Supervision appeared to be an important place for reflection as well as a place for organisational support and professional development. Several advocates were able to identify that reflecting and challenging themselves as to their role was crucial in the context of working with other professionals with differing opinions and perspectives, safeguarding concerns, or to consider whether their practice was upholding or challenging for the rights of the children and young people they worked with:

It is then a case of coming back, taking yourself out of the situation and looking at it objectively as well; looking at other explanations. Sometimes talking it through with somebody can really clarify it or open you up to looking at it from a different perspective. It's a really important part of advocacy. Being able to talk to somebody about it, is really hugely important (AM).

Reflection can be facilitated through supervision, but, certainly in social work, reflection and reflexivity should be in everyday practice (Payne, 2002). Whilst a non-instructed advocate is not working as a social worker, they are observing, gathering information from others (assessment) thinking about how to interact and considering whether they need AAC's (planning), then recording their findings similarly to a social worker assessment, planning, intervention and evaluation process. Reflexivity extends the concept of reflection "on" and "in" practice (Schon, 1983) in that reflection informs future practice and may also involve giving consideration to *context* of practice (Knott and Scragg, 2016). The extent to which advocates were truly reflexive in their practice to support children and young people's voices was not clear. Nevertheless, several advocates commentated that looking at the vignettes and thinking about

advocacy within the interviews, made them consider certain issues within their own, or their agencies practice. To be effective and productive, reflection has to be “critical reflection” based on both knowledge of rights, policy and legislation and the evidence of observation, not just on feelings (Fook, 2007). It is difficult to determine how effective reflection or indeed reflexivity of some advocates could be, considering their unfamiliarity with legislation and policy directly relating to the children and young people they were working with.

Advocates were aware of the importance of being a conduit for the child's voice, but nevertheless expressed concern as to their ability to do this fully. Some advocates demonstrated that they had taken time in “preparatory empathy” and in “tuning in” to understand issues and barriers to communication (Shulmann, 2009), but still expressed that:

...it can be quite frustrating for you as well because you think, have I picked up on everything that they wanted to tell me? (AV)

It is never fully' know' whether you have accurately captured entirely the voice of that child or young person. You can share your observations and information gathered, but there will be situations where you can't 100% be sure what that young person is thinking or how they are feeling if, even they, are struggling to share how they are thinking and feeling (AL).

Tobi's advocate also shared concerns after advocacy interactions that they could never be absolutely sure that they had supported Tobi's voice fully. Yet Tobi's advocate demonstrated a high level of reflexivity and self-awareness 'epistemic reflexivity' (Kinsella & Whiteford, 2009) around Tobi's communication. Whilst there was a correlation between experience and training, and in-depth answers demonstrating knowledge and understanding of legislation, this questioning of advocates own practice and self-burden to accurately capture the voice of the child or young person they worked with was made by the more and less experienced and trained advocates alike.

When asked about the challenges of doing non-instructed advocacy, several advocates spoke of their acute awareness of their unique role and were burdened with a *'sense of responsibility to show evidence of work and juggling contract obligations'* Ref 1.4. 'Juggling contractual obligations' may be regarding time, but also may lie deeper in the 'juggling' associated with the challenge of flagging up issues with the very same organisation paying for the service provided. This was raised when talking to 'live case' advocates, as well as interviewed advocates and within Medway SCR (Walters, 2019) and the most recent Children's Commissioner's report on advocacy in England (Longfield, 2019).

Concluding Comments

In this chapter the child or young person's 'voice', and the advocate's support for that voice through giving of 'space' and 'audience', has been examined. Advocates can act as a *conduit* and *facilitator* of support to enable children and young people's participation in decisions in a child or young person's everyday lives as well as for 'big decisions' such as transition planning or school move.

Interaction with a child or young person to build up a relationship was seen as important by advocates in order to support the child or young person's expression of their wishes and feelings. However, sometimes direct interaction was not possible. Advocates in live cases were receptive and reciprocal of children and young people's expressed communication and this enabled 'space' and 'audience' for the child or young person's 'voice'. Advocates were aware that changes in behaviours were indicative of children and young people feelings and through observation and talking to staff, were able to deduce some meaning, and thereby support a child or young person 'voice'.

Time to support a child or young person was seen as vital by advocates across the study. Seeing children or young people in different settings was also considered very useful, and often possible in issue-based 'case advocacy'. Residential 'visiting advocacy', where commissioning is by the setting itself, can enable relationships with children and young people to develop and thereby offer 'support' for their voice in everyday issues of care. However, criteria and rates of referral for 'non-instructed advocacy', were inconsistent across the Local Authorities represented. Often children and young people are 'out of area' if they are in residential care, which can lead to a breakdown in advocacy provision for statutory matters, such as safeguarding. The child or young person's 'voice' in these cases are not supported by independent advocates, and this is of serious concern.

Under Article 12 of the UNCRC, children have the right to support to enable them to participate in decision-making. Advocates support the child or young person's 'voice' in everyday matters as well as big decisions affecting the child or young person's life, by facilitating 'space' and 'audience' for their voice. Some of the advocates raised themselves that they felt they lacked the experience and/or training in communicating with children and young people with complex communication needs, thereby impacting on the 'support' offered. Many advocates were not familiar with legislation and policy around advocacy and rights. If support is not available or appropriate, there is a danger that the voices of disabled children and young people, particularly with complex communication needs will not be heard. 'Space' and 'audience' for children and young people 'voice' requires access and provision through skilled advocates with sufficient time to get to know the child or young person. However, this is dependent on the macro level; local authority and ultimately, wider political and societal will, to fund independent advocacy.

It could be argued that the children and young people represented within this study, through the life cases and cases cited by advocates in interviews, were

being supported to participate in decision-making, thereby demonstrating societal 'value' for their voice. However, statistically they were part of a very small number of children and young people able to access advocacy.

In the next chapter, the element of 'regard', stated in Article 12 UNCRC for the child or young person voice, is explored. Whilst a child or young person expressed voice can be supported through advocacy, the 'influence' of that voice; the extent to which that 'voice' can impact on decisions being made, must be also considered.

Chapter eight: Regard; the legacy of hearing children and young people's 'voice' through advocacy

In chapter six, children and young people's *expression* was considered and how advocates sought to understand the expression in terms of context, intent, and through dialogue with others. In chapter seven, *support* for children and young people's expression through advocacy was considered, from the micro of the child or young person-advocate relationship, to the facilitation of advocacy within the macro system of legislation and policy in England. In this chapter, *regard* for the children and young people's expression will be examined and discussed.

Unlike expression and support which are *assurances* under the UNCRC Article 12, *regard* to a child or young person's voice is conditional on the 'age and maturity' of the child - it is a 'possibility'. Yet, without a degree of influence, being able to express and been supported to express becomes meaningless - at best a tick box exercise to pacify. Disabled children and young people with complex communication needs have voices. Their rights are violated, often ignored or not fully recognised compared with their peers; their voices can be lost, ignored and unsupported, not necessarily through deliberate action, but through lack of willingness to hear those voices and crucially act upon them (Liddiard et al, 2019; Greathead et al, 2016; McNeily, McDonald & Kelly, 2015; Nind, Flewitt & Payler, 2010; Mitchell et al, 2009; Knight & Oliver, 2007). Yet Article 12 also enables *representation* for a child or young person, and Article 12 should be taken in context of all the Articles of the UNCRC. Whilst regard for a child or young person

voice in terms of influence can be negated by Article 12's caveat 'age and maturity' and the overriding principle of 'best interests', visibility and hence the challenging of violations of UNCRC articles in general, are enabled through the observance of the lives of children and young people.

This chapter begins by examining the role of advocates in *regard*. Advocates are a tool to *support* expression of a child or young person's voice, but without also *regard* for that individual child or young person voice and for the child or young person's voice to have 'audience' and 'influence' (Lundy, 2007), the voice will be lost. How advocates demonstrated regard for the voice of the child or young person will be firstly considered, before the role of the advocate as *conduit* and *challenger* for regard for the voice of the child or young person discussed.

Focus will then turn to the wider picture of the ecosystem of the child or young person in giving 'space', 'audience to' and 'influence' to the 'voice' of the child or young person. In previous chapters the context of the interaction between the child or young person and the advocate has been examined and the advocate working with others in the meso level. The macro level has briefly been considered in its impact on the 'support' for the individual child or young person's participation through advocacy. The ecosystem is the mechanism for information, control and facilitation of 'regard', hence advocacy and its role in 'regard' of children and young people's voice will be examined in terms of regard 'within', 'from', 'for' and 'despite' the ecosystem of the individual child or young person.

I conclude this chapter by examining two of the implications of giving regard for a child or young person voice. I consider the case for regard *not* to be given to a child or young person's voice in the child or young person's 'best interest'. I then give attention to the term 'non-instructed advocacy', arguing that the term may require consideration by virtue that 'regard' for the voice implies 'influence' and therefore instruction.

The sections of this chapter are as follows:

- 8.1 Advocate role in Regard
- 8.2 Regard for 'voice' in context of the eco-system of the child or young person.
- 8.3 Implications of Regard

8.1 Advocate role in Regard

As noted previously, a small number of the advocates who responded to the vignettes, demonstrated confusion and/or ignorance around communication of, and with, disabled children and young people with complex communication needs, despite the requirement to have carried out at least one non-instructed advocacy case to be part of the research (See Methodology, chapter four). Either they assumed verbal and competent cognition in communication despite clear descriptions of vignette cases, or conversely, assumed that no communication with the child or young person was possible. Both extremes are concerning as indicated in previous chapters. Particularly in relation to 'regard', the supposition of non communication by a child or young person strongly implies the advocate may not adequately provide 'space' and 'audience' in practice, let alone 'influence' for the voice of the child or young person.

Regard and enabling 'influence' are dependent on *receptivity* of the advocate (Greathead et al, 2016; Nind, Flewitt & Payler, 2010; Bunning, 2004). Nevertheless, the majority of the advocates interviewed using the vignettes and all of the 'live case' advocates, demonstrated a degree of regard for the voice of children and young people. Without regard for children and young people's voice themselves, advocates would not be in a position to be able to act as a conduit or challenger for regard to the wider ecosystem of the child or young person. It

is therefore crucial to explore the depth and range of advocate practice signifying 'regard'.

Advocates demonstrated regard for a child or young person's voice in their actions and reactions towards the child or young person themselves. On one visit to Sasha, the advocate and staff made the decision that Sasha was too agitated for our visit to be of benefit and may indeed have been detrimental. The cause of Sasha's behaviour was not known and unlikely to have been our visit, but the advocate's concern for Sasha's wellbeing demonstrated a regard for their communication. Regard for Sasha's voice in this incident was that the visit not go ahead.

Throughout the observations, there were many instances of reactions to behaviour that indicated regard for the individual wishes and feelings as interpreted by the advocate. Sometimes these actions and reactions demonstrating regard were **subtle**; such as the advocate carefully stepping over Sasha's arrangement of objects on the floor, reciprocation of ball-rolling between Tobi and Tobi's advocate (as described in chapter four), and the response by Kim's advocate to Kim's request for a particular computer programme.

Sometimes regard to a child or young person's expression was demonstrated in more **physical** actions, such as Tobi's advocate mirroring Tobi's body-language and lying on the floor - akin to intensive interaction (Goodwin, 2013; Hewitt & Nind, 2001). During the second visit to Rowan (where Rowan was able to communicate without support staff interrupting), Rowan indicated that they wished both the advocate and me to see another room. Standing up and being led by Rowan gave audience and crucially 'influence' to Rowan's voice; it was a very physical manifestation of the 'influence' facilitated through the advocate giving space and audience to Rowan's voice by being led. Rowan exercised agency and was very much participatory in the advocacy process - both in short-

term instantaneous decisions such as this, and in the longer-term decisions for which advocacy was accessed.

The absence of a demonstrative and instantaneous reaction to a child or young person's expression did not mean the advocate had little or no regard for the child or young person voice. Sometimes, such as the visit to Rowan, staff or environmental factors can mask the regard given to child or young person's voice at the time. Kim's advocate observed Kim's reactions to what staff were saying about an upsetting incident and to Kim's apparent reluctance to going outside. At the time, the advocate did not show regard for Kim's expression through direct action or reaction. Yet, in **subsequent dialogues** with staff and myself, it was apparent that the advocate was receptive to Kim's expression and was influenced by that expression and asked questions on Kim's behalf. Regard for Kim's communication by the advocate was evident. Dialogue and reports by advocates for the purposes of others was a significant and concrete indicator of the advocate's regard for the voice of the child or young person; what they noticed, noted and consequently reflected.

Advocates also demonstrated regard in **recognising atypical behaviour** for that child or young person may be a form of communication to be noted:

It is about finding evidence of behaviours of wishes and feelings- but also behaviours that are out of character that might indicate something else is going wrong. Also reporting things that you think might be significant in the future. A5b

In the vignettes, many advocates also collaborated this, largely stimulated by the Billy vignette and her reaction to the mention of Jake. One advocate spoke at length about a child showing distress by smiling and laughing that could easily be misinterpreted. For this advocate, regard for the voice of that child was also informed by the information from people close to that child to understand this 'atypical' behaviour as indicative of an issue.

However, ‘atypical’ communication through behaviours (Hannon & Clift 2013, Caldwell 2012, Dan 2008, Petry & Maes, 2006) was also recognised by many advocates to be ‘typical’ for the individual child or young person, such as Dylan’s self-biting. Whilst recognising that Dylan was communicating by his behaviour, advocates were also concerned about the physical self-harming impact of this behaviour. One advocate spoke of the difficulties of working with a young person who always pulled the advocate’s hair in greeting. Regard for the voice of the child or young person even if this voice is not understood or not ‘socially acceptable’, can be a challenge for advocates. This indicates a need for training and skills in coping with difficult communication, perhaps through input by speech and language and psychology and other professionals. This could lead to greater understanding in order to develop ‘regard’ for the child or young person’s voice through appropriate provision of ‘space’ and ‘audience’.

Advocates as Conduits of Regard

Within the microlevel of the child or young person/advocate relationship, the ‘influence’ the child or young person’s expression has on the actions and reactions of the advocate and how the advocate represents the child or young person’s voice to others – as a *conduit*, will now be considered. Within an advocacy session, advocates frequently responded and acted as a conduit. During one observation, Tobi was sat in a chair between the advocate and carer. As a researcher, I read Tobi’s body language to be indicative of boredom and tiredness, particularly given the context of the time, length of visit and environment. Tobi’s advocate also drew conclusions from Tobi’s non-verbal communication and attempted to relay this to the carers:

At least three times the advocate pointed out that Tobi appeared to be tired and fed up. Although Tobi did not attempt to leave the chair, [Tobi] was looking round, mouthing, and leaning to the side.
Obs A3

Tobi's advocate not only was aware of gesture and non-verbal communication but also took note of it and acted upon it by raising their observations with the carer. The advocate became a *conduit* for Tobi's expression through their own 'regard' for Tobi's voice, and supported this voice to be regarded by the carer. (It would not be appropriate for me to comment on the 'regard' demonstrated by the carer in this instance).

Acting as a conduit can also be in detailing observations from which conclusions can be drawn as to the wishes and feelings of the child or young person, and due regard given to this over time. With issue-based advocacy, 'regard' by the advocate, and the advocate subsequently acting as a *conduit* for 'regard', is often based on the advocate's observations regarding particular issues. With one of the CYP, there was an issue with a potential change in education placement, with divided opinions as to the best placement particularly in regard to peer interaction. In this case, the advocate used an amalgamation of observations of interactions with peers. The difference of reaction of the CYP to peers within and between the two settings, enable the advocate to evidence that the CYP did indeed seek peer interaction, and this should therefore be a consideration by decision-makers. As with Greathead et al (2016) and Simmons and Watson's (2010) findings, context and different settings and observation of difference enabled the child or young person's 'voice' to be expressed and regarded. The advocate's work was not to decide on the best placement but to allow the 'influence' of the voice of the CYP by giving 'space' and 'audience' through careful observation; thus giving due 'regard' for the CYP wish to have peer interaction.

Some advocates in the vignettes indicated that ongoing visiting advocacy enabled a sense of 'regard' for the wishes and feelings of a child or young person to surface, particularly in observation of reaction to change. This was clearly demonstrated by the experiences of Sasha and Sasha's advocate. Sasha's advocate had noted the reports that Sasha had taken to picking paint and plaster off the walls in recent months, to the extent that it had caused damage to Sasha's

fingers. However, this had been after the walls have been painted a different colour. As an observer, the advocate remained open-minded (Lyons, 2003) and also demonstrated - 'reflective practice of epistemic reflexivity' (Kinsella & Whiteford, 2009), enabling the advocate to consider other explanations for Sasha's behaviour. The advocate felt that Sasha was unable to communicate displeasure verbally but reacted to the environment by attempting to reverse the painting which had been done. The advocate had wondered how much consideration had been made by decision-makers as to the effect on Sasha, particularly given that Sasha had no engagement in decision-making about paint colours. Through observation and reflection, giving 'space' and 'audience' to Sasha's expression, the advocate interpreted Sasha's actions over time, and facilitated 'influence' by raising the issue with management.

Within the Billy vignette, most advocates stated that they would need to pass Billy's reaction and behaviour, following the mention of Jake, on to another party. Of concern was that responses from two advocates indicated that they did not consider underlying issues for Billy's communication but focused on the consequences of the behaviour. Regard for what Billy was saying, whether they understood it or not, was not a priority; they acted as 'gatekeepers' rather than conduits for regard from others. Nevertheless, the majority believed that Billy's reaction was indicative of an issue, whether this was as significant as a safeguarding concern, or expression of feelings about Jake and Trisha's relationship. Of those advocates that consider this to be a potential safeguarding issue, the majority recognise that their role was to act as a conduit rather than an investigator.

Advocates as challengers for regard

There were many instances within the 'live cases' which demonstrated that the advocates took what they had observed and used this to inform and influence their communication to others. In addition, there were incidences where

advocates demonstrated not only their role as a conduit, but as a *challenger* for regard from others vis-à-vis the child or young person voice. Rowan's advocate clearly demonstrated role as challenger for regard for Rowan's expression by questioning staff as to the absence of signing and use of iPad. The advocate was aware that, without the AAC, Rowan was hampered in their expression, and the regard for Rowan's voice was being thus negatively affected.

Many advocates in the vignettes collaborated this and felt that the recognition by others for the 'voice' of disabled children and young people with complex communication needs was a major obstacle to challenge. Their role included confronting other professionals, in particular social workers, to take note and listen to a disabled child or young person:

If advocacy wasn't involved, how long would that have gone on for? (case) Just because (a disabled CYP) can't get on the phone to the social worker ranting and raving about how rubbish they are- the ones that shout the loudest get the biggest response. Other professions are too busy with things and not focusing on the child.
AV

I think I am a bit more threatening for social care professionals if I point out that they have the same rights as other young people and you need to be listening to them, and if you don't listen to them or I think you're not listening to them, I am going to challenge you on that. Reminding them of that. AW

Challenging attitudes and expectations around the voice of the child or young person is not unique to advocacy (Pluquailec, 2018; Browne & Millar, 2016; Georgson et al, 2014; Franklin & Sloper, 2008). Regard for the child or young person voice was understood by advocates to need thoughtful but nevertheless necessary handling. The majority of advocates spoke of the need for sensitivity and diplomacy in their interactions with other professionals in challenging for rights to be upheld. This was very much evidenced in the 'live cases' observed. All four observed advocates spoke of their awareness and potential awkwardness and 'internal dilemmas' arising from their unique role as advocate:

[We spoke of] the issue of sticking your hand up, to stand up for the rights of a child, but trying to do it in a way that doesn't put peoples backs up.[Advocate] expressed they felt guilty about being a trouble maker, but also felt that the advocacy was like that. REF1.2

The status of advocacy as a legitimate tool for participation is a significant issue for advocates. Recognition as a facilitator and conduit is difficult enough, but advocates challenging for regard for the child or young person can be resisted within the meso level. This will be considered in greater depth shortly.

Notes and reports of advocates have the potential to act as a conduit for children and young people, but also to challenge rights of children and young people. They can be a tool to demand 'audience' and opportunity for 'influence'. Reports, verbal or email interactions, around rights, resources and choices emerging from observations and interactions by advocates with children and young people were cited throughout the study in both on-going and case advocacy. Yet, the boundaries and remit of the reporting and questioning appeared to be a concern to advocates, and some expressed that their reports or questions were sometimes not understood and/or taken seriously by others. As highlighted previously, the response to advocate interactions with other professionals can be mixed, as AW states:

For them to take them on board and take action about them [questions]- I get very mixed response. Some just don't seem to listen at all, others find it really find it helpful [advocacy]- and it's really brought that young person to the centre of the plans. AW

Yet persistent, consistent and informed reporting was seen as vital for the child or young person's voice to heard and regarded:

.... it's not my personal view, my professional view or anything like that about what I think should happen.... I try to explain it, and clearly explain it in my reports- what I've done and how I have come to these questions that I am asking them. AZ

The advocate acting as conduit and challenger involves the ecosystem of the child or young person by virtue of being a conduit to, and a challenger of, or for, rights. Attention will now turn to the advocate role within the context of the ecosystem of the child or young person.

8.2 Regard for voice in context of the eco-system of the child or young person

In the previous section, advocate receptivity and regard, and the advocate role in acting with, or on behalf of the child or young person's voice was considered. It is clear that it is difficult to isolate advocacy working with a child or young person, without considering the context in which the child or young person is; their ecosystem.

In previous chapters the context of the interaction between the child or young person and the advocate has been examined and the advocate working with others in the meso level. The macro level of children and young people's lives has briefly been considered in its impact on the *support* for the individual child or young person participation through advocacy. The ecosystem of an individual functions where there is both input and output; giving and receiving; the child or young person in the centre is not a passive receiver when facilitated to give; to 'influence' the micro, exo and macro, through receptivity of communication. The ecosystem of the child or young person must be regarded in giving 'space' 'audience' and 'influence' to the received 'voice' of the child or young person.

The position of 'regard' in the context of the ecosystem of children and young people and advocacy working, can be categorised as follows. *Regard within*; how

professionals and carers regard the voice of the child or young person through the tool of advocacy. *Regard for* micro-level of the parent/child or young person relationship and their interpretation of the wishes and feelings and needs of the individual child or young person, and the regard for the culture and community of the child or young person and their family by advocates. *Regard from* the meso, exo and macro level in consideration of provision of advocacy as a tool for support in order for the child or young person's 'influence' to be understood (Macro and exo level). This also extends to the recognition of rights of confidentiality and dignity in advocacy working. Finally, *Regard despite* relationships within the ecosystem; advocate working to regard for the individual voice and separating this from the opinions of others and challenging for the child or young person's voice to be regarded as unique and individual.

Regard within

Within this section, how professionals, carers or parents regard the voice of disabled children and young people through the tool of advocacy will be addressed. It is well documented the low percentage of disabled children and young people accessing advocacy (Longfield, 2019; Adams et al, 2017; Longfield, 2016; Brady, 2011; Franklin & Knight, 2011). It could be assumed that someone, somewhere, valued the voice of the individual child or young person and advocacy practice for a referral to be made. Yet advocates reported that a significant challenge they face is:

professionals, carers and family members respecting non-instructed advocacy as a legitimate tool. AX

As explored in previous chapters, there may be some issue over the terminology, and therefore knowledge of services available. Nevertheless, several advocates identified an issue with attitudes towards advocacy or scepticism as to the legitimacy of non-instructed advocacy, particularly from non-referring parties:

Social workers can vary.... If the referrals come from elsewhere, some of the social workers can give the impression that they don't think that an advocate is needed- sometimes without saying it in as many words, you just sort of get that impression. AL

After overcoming the initial hurdle of recognition of the rights for and/or existence of advocacy, advocates commonly mentioned the issue of expectations of other professionals and the boundaries of what 'advocacy-is-not', can sometimes become a challenge in interactions with others:

what I always explain to other professionals, is that we as advocates, are not decision-makers. AJ

It is not necessarily my job to educate a social worker about non-instructed advocacy, but if they don't know and they don't have the skills, or if they've been given the wrong information, or misunderstood then it is my duty to say 'this is the work I will be doing with this client and this is the authorisation I have to do that'. AX

Evidence from advocates across the study indicates that sometimes advocates can be mis-understood as "rubber-stampers" to decisions already made; a tokenistic nod to the rights of a child or young person to participate:

Really difficult to get social care to listen to young people- not to use advocacy as a tick box exercise. AW

In this, 'regard' towards the child or young person's voice may be evident from the advocate, but the regard for that voice within the ecosystem is diminished, sometimes to the extent of completely negated. This makes the work of the advocate seemingly meaningless. I use the term 'seemingly' because advocates can change perceptions, and without advocacy in place, there will be no avenue for advocacy to influence for change as to regard for the voice of the child or young person within the child or young person's ecosystem. Managing expectations of other professionals is more complex than the specific interaction between one advocate and a social worker; there are implications from and for

the macro level in which advocates work, including the training of social workers and other professionals as to legislation and policy around advocacy.

Despite many reports of negativity, some advocates also cited instances where professionals, particularly social workers, had appreciated and valued their work and engaged in referring for the children and young people they worked with:

If the referral comes from the social worker, we find that they are very much on-board. AL

The 'live' observed advocacy cases, the welcome of the *settings* indicated that the work of the advocate was excepted at the very least.

Regard from

In this section, *regard from* the eco-system *towards* the child or young person's voice will be considered. Firstly, how the value of basic human dignity and confidentiality for children and young people is negotiated by advocates as facilitators and challenges to regard for children and young people by others. Secondly, how regard from the wider ecosystem of the child or young person is expedited to the individual child or young person by the giving of 'space' and 'audience' directly through the tool of advocacy.

Rights of dignity and confidentiality

Regard in the context of Article 12 and Lundy's elements of participation is in 'influence' (2007) attributed to the child or young person's voice. Yet the *value* given to human rights of confidentiality and dignity are indicative of regard in the broader sense of recognising humanity. For advocates negotiating the rights of children and young people to confidentiality and dignity are basic, every day, on the ground values to challenge, well before the fight to convey the wishes and

feelings gleaned from interactions with the child or young person. The advocate role in promoting the specific rights of a child or young person to dignity and confidentiality will be addressed in depth, as they are key issues in the context of advocacy interactions within the meso system, particularly in relation to paid carers and professionals.

The Shabnam vignette in part 3 was used to stimulate conversations around rights of dignity of a child or young person and confidentiality.

Shabnam part 3:

You visit Shabnam in her Respite placement several weeks later. Shabnam is sat around a table in the dining room with 3 other clients and 2 staff members. You establish eye contact with Shabnam, and she responds positively, you talk to her in a low quiet voice and she continues to look at you. A staff member then sits the other side of Shabnam and starts telling you (in a loud voice) that they think Shabnam has an issue with her hormones and periods and mum doesn't really care.

While some advocates said they had not experienced staff acting this way or overstepping the bounds of confidentiality, many advocates recognised the familiarity of this scenario, particularly when working in non-instructed capacity:

...staff to tell you things when other people are present. Sometimes it can be 'well that person doesn't know what is going on in terms of this person, so I can openly tell you'... So yes, it does happen. AZ

Recognising this scenario as poor practice on the behalf of the staff member, or not appropriate was almost universal across the advocates interviewed:

It's quite inappropriate and disrespectful to Shabnam, whether she understood it or not It's a bit like talking about someone over the top of their head. No, I would not be happy. AJ

Dealing with this scenario, however, was a challenge to many advocates:

I would halt that conversation and tell the staff member it was not appropriate to discuss that in the environment with other people around and perhaps we could have a quiet conversation about that with Shabnam possibly- Afterwards I would make it very clear that I didn't think it was appropriate having that conversation with me in front of the people. I would point out the dignity issue. AM

A few suggested that they may take the issue further with management.

obviously speak to staff afterwards- it's about treating people with respect, it's just not appropriate to say that in front of other people but also in terms of saying things like about hormones and periods and then actually just saying mum really doesn't care because... just shouldn't be saying things like that. It's just not professional and it's something I would raise definitely. AY

...make sure that staff members not breaching Shabnam's confidentiality and dignity. Perhaps even flagged this up with that person's manager. It's poor practice to be honest isn't it? AX

Within the live cases, on several occasions and not confined to one setting, different advocates were placed in a situation whereby staff started to talk about a child or young person in front of others (not just the researcher) or discussed other children or young people, staff or management issues in front of the child or young person. For one CYP, a health issue was raised by a care worker in front of a number of fellow CYP and staff. The advocate at the time did not challenge the appropriateness of this but reflected afterwards that they felt they could not ask to continue the conversation in private because of the lack of facilities to do so within the setting. One CYP had been involved in the safeguarding incident, which was being discussed in front of them, but involved other CYP, and staff management issues. As an observer I reflected:

During the visit, staff were very open about the incident in front of [CYP]. I felt a little uneasy, not because [CYP] was there and they were discussing the incident itself, but they were expressing concerns about management, and the issues with the other young person. REF 4.a

It is unfortunate that many advocates felt the Shabnam vignette ran true to their experiences. Advocates spoke of witnessing a particular *culture* within care settings and the difficulties of not being drawn into colluding with the 'culture' of the setting. Within the live cases, there were incidences observed where possibly the 'culture' of the setting impacted on the advocate relationship with their child or young person, but no further details will be divulged in order to protect identities. A few advocates within the whole study reflected that the issues of dignity, respect of person and their family, and rights of confidentiality, had both implications for, and stemmed from, beyond the meso level of the child or young person:

Whether it's an issue of complacency on behalf of the staff I'm not too sure, but it does need to be addressed. Is going to impact on the young person AL

it's a kind of desensitisation- not seeing the person and behaving in a way that you wouldn't behave with any other adult. You would dream about that, or interrupting conversation that they were already having with someone else even if it wasn't a verbal conversation. AM

Notwithstanding, within the live cases there were many instances where advocates and staff around individual children or young people worked together to ensure dignity and confidentiality. For example, carers checked that a particular CYP had dressed appropriately after a shower before coming into the lounge area to meet the advocate. This sensitivity was commented on positively by the advocate. A number of staff across the settings asked individual children or young people if it was ok to talk to the advocate about something before addressing the advocate. The advocate asking for consent or looking for assent, was particularly noted for two advocate's practice when it came to asking others about on-going issues on behalf of the child or young person.

Regard from the wider ecosystem for the voice of the child or young person

The recognition of a 'culture' of disregard may be significant in understanding the advocacy relationship in terms of negotiating, challenging and possibly facilitating rights of the children and young people within the meso-level in the context of the macro. Within the vignettes, several advocates alluded to the issues of attitudes from the meso, exo and macro system for the voice of the child or young person:

It's a culture really of talking about them and not respecting them and applying a different set of rules to them. AM

Raising the profile of disabled children and young people voice, and advocating for 'influence' for that voice, is advocacy in the wider context of society is an issue for advocacy services in general as highlighted by NDTi findings (2016).

Despite advocacy practice observed clearly demonstrating regard and advocate acting as a *challenger* and *conduit* for regard, the degree to which the voice of the child or young person was regarded in exerting any 'influence' was difficult to determine. The issue of lack of access to advocacy around safeguarding and statutory matters because of the residential status of disabled children and young people cited by advocates across the study, implies that the regard for the voice of children and young people in these crucial matters is not recognised by the wider macro level of local authority, and ultimately, government. This is an area for further research.

Regard for

The context - the ecosystem of the child or young person cannot be easily isolated from the child or young person themselves. Regard therefore for the voice of ecosystem of the child or young person and the lived experience of the

child or young person must be considered. The ecosystem is influenced by, and an influence on, the child or young person. Focus will turn to regard for parents, and then the regard for children and young people's community and culture.

Parents

Previously the evidence of parents being significant in understanding a child or young person's *expression* has been explored, as has the role of parents in *support*. Parents of disabled children and young people are recognised as significant in the ecosystem of disabled children and young people (Kruegar et al, 2019; Davey, Imms & Fossey, 2015; Mitchell, 2012a), and in advocating for their child (Kruegar et al, 2019; Adams et al, 2017; Longfield, 2017; Burke et al, 2018; McNeily, McDonald & Kelly, 2015; Brady, 2011). Whilst regard for a parent's voice is not regard for the child or young person's voice, it is often parents raising issues for their child; advocating on behalf of. This is consistent with the role of a 'representative' recognised within Article 12.

Several advocates showed an awareness of families interacting with elements of the macro system. This may be through family members pressing for resources with the local authority and needing to go through legal challenges to change policy or decisions made. There was some consensus that often parent's concerns were related to whether their son or daughter was provided with the resources they needed:

they think or they feel that their child isn't getting what they should be getting. Sometimes they are absolutely right and there really is a gap in provision. AJ

Some advocates also cited cases where parents felt shut-out - that their role in being a 'voice' for their child, was dismissed, and therefore the possible 'influence' of their child's voice was not facilitated, despite them as parents giving 'space' and 'audience' to their son or daughter's voice. Again, advocates

were aware of the dilemmas around separating parent voice from that of the child, yet had empathy with parent's dismay at the perceived lack of regard for their role as a conduit for their child's voice, particularly in decision-making around transition from child to adulthood:

One day they are 16 and then the next day they're 17, or 17 then 18, depending on the legislation, and overnight their rights as a parent to make decisions are gone. And all of a sudden, they are sat in a room full of professionals making best interest decisions. I think it's really difficult for parents to understand and deal with.
AX

When considering the vignettes, some advocates asked questions regarding the health, learning disability and language barriers of parents, with the explicit function of ensuring they had the bigger picture of current interventions and a greater understanding of the family and potential impact on the family. Whilst all advocates declared they were all heedful of their remit to be the child or young person's advocate and not the parents, in the live cases, three advocates described how they had highlighted the needs of the parents to social workers or other professionals. This could be deemed as advocating on 'behalf of' parents. Intervention on behalf of parents was justified by the advocates in the cases described, because of the resulting positive impact on the child or young person.

One advocate stressed that in their opinion, non-instructed advocacy is not the same as instructed advocacy in terms of boundaries with parents and family, and that they were acutely aware of the strain on parents with severely disabled children. Several advocates raised the prospect of referral for parental advocacy. One advocate also highlighted the gap in support for disabled childrens' parents compared with carers of people with Alzheimer's for example. Whilst this is again beyond the reach of this thesis, the measures and support for parents - often vital as long-term care-givers and advocates for their sons and daughters, should be considered.

The community and culture of the child or young person

In the vignettes, Dylan, Shabnam and Billy are described within the context of their family circumstances, highlighting issues not only of advocates managing parental expectations, but working in the ecosystem of the child or young person including language and culture, and the interplay of families within the care, education and medical services. In the Shabnam vignette, issue of language and culture were prominent. Many advocates were sensitive to understanding the issues that Shabnam's mum was raising about the respite centre:

I would be wanting to know why she thinks a respite centre is not meeting her cultural needs. What is it exactly? Is it the food, is it the activities, is it the people that she is working with? Try and get to the bottom of that... Shabnam's rights for her cultural needs to be respected. AW

I would also be having an open conversation about what her cultural needs are, and that the respite centre understands them. Not just about what things are important, but why things are done. So it's about further training with the respite centre. AM

A number of advocates stated that given the demographics of their area, there was a disproportionate lack of referrals to their service from the 'Black, Asian, ethnic minority' [BAME] cultural communities. One advocate offered an opinion that this might be to do with a reluctance to ask for help. Yet as Cohen (2013) and Fazil et al (2004) suggest, stereotyping is prevalent amongst social and medical professionals. Advocates are working in this context, but also may themselves be insensitive and/or prejudice. Whilst in the research of Fazil et al (2004) advocates were recruited from within the Bengali and Pakistani communities, all the advocates in this study were white British. The fact that children and young people from BAME families may be less likely to utilise advocacy services has a potential impact on the individual to have a voice, but also has implications for the wider meso and macro systems regarding services and/or policy and working with BAME families and thus demonstrate 'regard' for

the ecosystem of children and young people. Engagement levels with advocacy within BAME communities is suggested for further study.

Two of the parents contributing to this study spoke of the isolation they felt having a child with complex needs, particularly as their child's development and behaviours became significantly divergent from their peers as they grew. A lack of understanding by the people around them- family and friends included, had a toll on the parents' well-being. This underlines previous research concerning the support of parents own eco-system (Davey, Imms & Fossey, 2015, Cohen 2013, Fazil et al 2004, Dowling & Dolan, 2001) impacting on the child or young person. 'Regard for' the community may also involve recognising that disability can still be a taboo issue. 'Educating' the wider community to value disabled children and young people; to change the ecosystem of the child or young person is too complex to consider here, but worthy of further consideration.

Regard Despite

Regard for the individual voice and separating this from the opinions of others can be problematic. Many advocates spoke of maintaining independent 'integrity'; the complexity of both listening to the opinions of others in order to gain information regarding the child or young person's care and support, whilst managing the potential for being "drawn in" and appearing to agree with other professionals' opinions:

When (a CYP has) limited communication or is non-verbal, it is difficult not to be influenced by others. AY

Knowing what staff or parents wants as opposed to what the young person wants... big challenge is trying to stop staff and parents interfering and tell you that's what they're saying when you're not sure that that's what they (CYP) are saying at all. AP

Many advocates also spoke of the conflictions of dealing with children and young people and their parents, yet agreed that the parents should be listened to, so

that they were part of the process around their child in terms of feeling their opinion was heard. There was some consensus that often parent's concerns were related to whether their son or daughter was provided with the resources they needed. Nevertheless, advocates were almost unanimous in stating that regard for the child or young person's voice as unique and individual, was an essential part of advocacy, and important despite the challenges posed in working within the ecosystem of the child or young person.

As previously described, advocates across the study gave examples where they had challenged the meaning of a child or young person's expression and challenged for support. Advocates, whilst working within the eco-system, give 'space' and 'audience', despite obstacles and barriers from the ecosystem of the child or young person. They undeniably give 'regard' to the child or young person's voice in their advocacy practice *despite* elements of the ecosystem as seen in descriptions within this chapter. Yet, as already discussed, advocates feel a sense of burden to work within the ecosystem and not 'rock the boat' too much in challenging others. Challenging for 'regard' to be given to a child or young person's voice, and for the 'influence' of the child or young person's voice to impact on rights of *provision* and *protection* has not been fully explored within this thesis. Yet as these rights are denied or not fully realised within the child or young person's ecosystem (Flynn & McGregor, 2017; Franklin & Smeaton, 2016; Cossar et al, 2013; Stalker & McArthur, 2012), it is clearly essential that advocates work *despite* the ecosystem to regard a child or young person's voice. The impact of this and further considerations as to the purpose and potential power of 'regard' for children and young people's voice will now be discussed.

8.3 Implications of Regard

So far in this chapter, regard for the child or young person's voice has been considered in the context of the micro-relationship with the advocate, and in the context of the ecosystem. It has been argued that regard for the child or young person voice is important, and part of the role of the advocate, is to act as a conduit or challenger for regard. In this section, the *implications* of giving regard to a child or young person's voice are reflected upon. Two aspects affecting advocacy practice will be explored. Firstly, the issues of balance when considering the overall principle of the UNCRC of decisions being made in the 'best interests' of a child or young person, and the implications of giving 'influence' or regard for the child or young person's expressed voice. Secondly, the question of whether regard can be considered as 'instruction' and therefore the term 'non-instructed advocacy' should be reviewed.

Regard and Best Interests

Within the text of this and previous chapters, I have made clear that I consider children and young people's participation to be important, not just for the big decisions, but in the small every-day decisions and choices in life. Whilst issue-based casework advocacy is often focused on 'the big decisions', advocates across the study have demonstrated awareness of the importance of the 'small' too, particularly for children and young people with complex communication needs. However, a child or young person's expression, may have *consequences* for other rights which may require the advocate not to take 'regard'. For example, Tobi running around and putting a small object in their mouth was potentially dangerous for Tobi, and required intervention rather than allowing Tobi to continue, which may have put Tobi in danger of choking.

It is important to return to the principles of Article 12, namely that ‘regard’ given for a child’s voice is dependent on the *capability*, *age* and *maturity* of the child. Regardless of *age*, Tobi was not able *capable* of understanding the consequences of running around with an object in their mouth, and therefore intervention was made in Tobi’s ‘Best Interests’. Regard; the ‘influence’ on the decision-making process, is as a *possibility* rather than *assured* right. Article 12, the focus of this research, also needs to be put in context of the other Articles of the UNCRC and the underlining principles of best interests, rights to life, survival and development, as well as respect for the view of the child.

Within the ‘live cases’, two of the CYP were being looked after in isolation from their peers in particular circumstances. The voice of one of the CYP to indicate they preferred to be with peers was observed. The advocate acted as conduit to decision-makers about the CYP indicated feelings, and due note was taken. However, with the another CYP, during isolation from peers, the CYP had become calmer and appeared to be more responsive to staff. Whilst ‘regard’ for the *immediate* voice of the CYP would indicate that the arrangement was favourable for the CYP at the time, the advocate was concerned that this arrangement may be an infringement of other rights, such as rights to relationships with peers, and opportunities around leisure activities. The advocate spoke of their intention to bring these concerns to decision-makers, as well as their observations about the CYP demeanour. The advocate was seeking to look beyond the immediate wishes and feelings of the CYP and convenience of staff which might swing the decision to remain with the current arrangement, to highlighting other rights of the CYP which may be adversely affected by this arrangement in the future, particularly regarding institutional isolation.

Ultimately an advocate’s role is to act as a *conduit* (Longfield 2019). They may also have to *challenge* decision-makers to give ‘space’ and ‘audience’ to the ‘voice’ and point out when issues may need to be addressed such as consulting with Sasha over colour of walls, or the fact that Rowan does need their iPad every

day, or that Eden wants to know when they are going home. The dilemma for the advocate can be when the ‘regard’ they have for the child or young person’s voice is then not regarded by the decision-makers. Yet advocates are *not* decision-makers, but advocates.

Regard as Instruction?

Within the five ‘live cases’, it was apparent that the individual children or young people; Rowan, Sasha, Kim, Tobi and Eden, were able to express at times their wishes and feelings, whether through avoidance, vocalisations, facial gesture or other action. Whilst there were some ambiguities in interpretation by others, communication by some means, was nevertheless evident. In this chapter, ‘regard’ for the voices of these individual children and young people - the ‘influence’ facilitated, has been demonstrated through the receptivity and consequential actions and reactions of advocates to the individual child or young person’s communication. In effect, ‘instruction’, by virtue of the ‘influence’ of the child or young person’s agentic voice, has been made by the child or young person to the advocate. Therefore, it is crucial to consider whether the term “non-instructed” coined by advocacy services, and increasingly recognised by other agencies such as the Children’s Commissioner (Longfield, 2019) is indeed an appropriate term for advocacy with disabled children and young people with complex communication needs.

One of the difficulties evident in the very first stages of this research, was in the definition and extent of use of the term ‘non-instructed advocacy’. Several social work texts and grey material from advocacy agencies and charities for disabled people (adults and children) within the UK refer to ‘non-instructed advocacy’ as a form of advocacy (Macadam et al, 2013; Brady, 2011; McGrath, 2010; SIAA, 2009; Lawton, 2006; Cloverleaf, n.d., Asist n.d, Voicability n.d). To date, there is no legislation that coins the term “non-instructed” advocacy in health or social care in UK. Nevertheless, the Children’s Commissioner of England (2016, 2019)

categorised and highlighted advocacy provision in terms ‘non-instructed’ for disabled children and young people with complex communication needs and / or very young children and babies. Defining ‘non-instructed’ advocacy may impact on legislation in the future if the term becomes more used in practice and policy documentation.

The definition given by the Children’s Commissioner of England in 2019 is:

advocacy support which does not require children to instruct an advocate- it is used for children who cannot lead the advocacy process e.g. children with disabilities or communication needs, or babies and very young children. (Children’s Commissioner for England: Advocacy for Children, June 2019, p. 11)

Such binary application of the term ‘instruction’ may also overlook the issues of ‘instruction’ and ‘leading the advocacy process’ for *all* children and young people. Being able to instruct an advocate may be an issue for many children and young people of all ages and disability status. Firstly, children and young people are not always aware of their rights to an advocate (Adams et al, 2017; Longfield, 2016; Taylor et al, 2015; Brady, 2011; Elsley, 2010). Secondly, advocacy is not always available (Longfield, 2019; Thomas et al, 2016; Esley, 2010). Thirdly, there is evidence that children and young people are not always aware of what they want, or confident to say or instruct in a short timeframe (Dalrymple & Boylan, 2013). Fourthly, advocates do not always put across accurately the child or young person’s views or even reporting the advocates view rather than the child or young person’s view (Moss, 2011; Morgan, 2008). Therefore, many children and young people could be categorised as not being able to ‘lead’ advocacy process. Arguably, advocacy as a tool to *support* the voice of a child or young person, is possibly *less* needed by a child or young person who is able to ‘lead’ and have ‘voice’ than a child or young person who is *not* able to ‘lead’.

Returning to the question of the term ‘non-instructed’, I am mindful that in the evidence from some of the advocates, and in my own experience, using ‘non’ in

the term 'non-instructed' advocacy can be a misunderstanding. It implies that there is *no* instruction, and the person is not participatory. Yet within this study, it has been clearly demonstrated that *instruction* was taken by advocates in their *regard* for the child or young person's voice and a recognition of their individual agency. The child or young person's 'instructions' were mostly non-verbal, and as a result of observation of the individual's 'expression' through body language and responses to questions or situations. It is also pertinent to consider that advocates that had the specific non-instructed advocate training and experience working within what is current known as 'non-instructed' advocacy, were able to demonstrate a high level 'regard' for the voice of children and young people and support their expression through giving 'audience' and 'space' appropriately.

Only one CYP could be described consistently as a locutionary communicator in that they were able to use signs, symbols to respond to and illicit communication spontaneously, yet *all* were able to make their feelings known to a receptive recipient of their communication. It is acknowledged that none of the children or young people within this study were operating at a perlocutionary level of intent, (little indication of intended communication, Ogletree et al, 2011). As previously discussed, 'voice' is the expression of the person's lived experience as well as their conveyance of their wishes and feelings. Further research with children and young people with perlocutionary intention is suggested to study their voices as the expression of their lived lives.

Advocates themselves were not able to explain where the boundaries of 'instruction' and 'non-instruction' lay. Whilst advocates all spoke of the importance of communicating with others around the child or young person, very few advocates indicated that this would be their *only* approach. Most felt that to get to know the child or young person through observation at the very least, would be appropriate, and as demonstrated earlier in this chapter, observations of the children or young people can be informative as to a child or young person's feelings, and thereby act as an 'instruction'.

Within advocacy circles, 'non-instructed advocacy' has perhaps become 'shorthand' for advocacy for disabled people with complex communication needs. Whilst giving a name for specialist advocacy provision may help advocacy providers in terms of resourcing and training their advocates, the term however might also be regarded as 'dis-abling' (Pluquailec, 2018; Goodley & Runswick-Cole, 2014). To differentiate between advocacy on the grounds of communication and or capacity, is to once again isolate and 'make different' their advocacy provision. All children and young people, regardless of communication needs have rights to express, to access support, and for their voice to be heard.

In chapter one, advocacy was described as a 'continuum of practice and purpose' (Wilks, 2012; Drake, 2009); representational through to empowerment; standing *behind*, to standing *with*, to standing *for* a person. It is recognised that *communication* can fluctuate (Bunning, 2004; Grove et al, 2000), and *capacity* can fluctuate (within the Mental Capacity Act 2005). Both are factors in the definition of non-instructed advocacy given by advocates themselves. In addition, differences between individuals, and fluctuations of communication given the *context* (Greathead et al, 2016; Simmon & Watson, 2010), of the individual child or young person at the time of advocacy interaction- as illustrated throughout chapter five, cannot be delineated simply into 'instructed' or 'non-instructed'. Therefore, to apply the binary term 'non'- meaning 'not' or 'no', does dis-service to the children and young people themselves as agentic communicators, and the skills of an advocate to facilitate communication and thereby 'instruction'. I argue that the binary term further disables the voices of children and young people with complex communication needs by perpetuating dis-agency and dis-voicing.

The term 'non-instructed' could be replaced by a term that better describes advocacy provision for people with complex communication needs that require specialist advocate support *on a continuum*. This will be considered further in the

following chapter. Access to advocacy is difficult for *all* children and young people, particularly in some areas. Despite concerns over the labelling of specialist advocacy as 'non-instructed', the differentiation by using the term 'non-instructed' has exposed the great divide in provision for children and young people with differing communication. The percentage of children and young people with disabilities and/or special educational needs [SEN] that require 'non-instructed' advocacy, falls far below that of other categories.

Concluding remarks

In summary, this chapter has sought to demonstrate that regard is given to the voices of children and young people by advocates in their practice. Regard by the advocate to the child or young person's expression, was demonstrated in the 'influence' of the child or young person's 'voice' in the advocate's actions and reaction, either immediately or over a period of time. Advocates gave space and audience to a child or young person's voice by being observers and facilitators of communication, but also acted as conduits and challengers for 'regard' of the child or young person's voice to the meso-level. The degree of regard given to children and young people's voices within their meso-level and beyond to the macro-level, appears to be influenced by many factors, including attitudes and values.

The ecosystem of children and young people is important to consider, giving regard for the context of the child or young person; their family, community and cultural voice. Yet the ecosystem itself may act as a barrier to the 'influence' of the child or young person's 'voice'. Regard for a child or young person's expression through the support of the advocate may be given despite the ecosystem of the child or young person. This chapter has also highlighted issues for advocates in working in the multidisciplinary context of health, care and education. Keeping the voice of the child or young person central appears to be

a constant issue, particularly in 'non-instructed' advocacy- advocacy for disabled children and young people with complex communication needs, because 'instruction' - explicit direction about an issue, may not be forthcoming directly from the children and young people themselves. Yet, I argue that with appropriate skills, knowledge, training and experience, advocates are able to determine a degree of instruction through their observations and interactions with the child or young person, and therefore give *regard* to the child or young person's agentic voice.

The role of the advocate in support of the expression of the child or young person, and crucially, to take regard for that voice has been demonstrated in this chapter and the previous two chapters in the advocates relationships with the children and young people in the live cases, and in the responses of advocates to the vignettes. The following chapter explicitly brings together the role of the advocate and explores how the advocate operates as an observer, facilitator, conduit and challenger for rights within the ecosystem of the child or young person.

Chapter nine: Towards a framework of advocacy practice with children and young people with complex communication needs

In this chapter the findings and discussions from the previous three chapters are brought together to consider how the rights of children and young people are actuated through advocacy. The conceptual framework of Lundy's four factors of participation, the three elements of Article 12 of 'expression', 'support' and 'regard' and the additional factor of 'value' will be considered alongside the theoretical framework of systems theory:

- In the first section the relationship between the child or young person's *expression*, the *support* given by the advocate, and the *regard* given by the advocate and the ecosystem is considered.
- In the second section, the question of instruction and 'non-instruction' as terms are deliberated in greater depth and a 'cube of instruction' with children and young people with complex communication needs is suggested.

- In the third section attention turns to the other articles of the UNCRC and how rights of participation can impact on the rights of provision and protection for children and young people.
- In the fourth section, the role of the advocate as observer, conduit, facilitator and challenger is explored and the advocates role within the ecosystem of the child or young person.

Finally, attention returns to the facilitation of a child's participation through Lundy's factors of 'voice, space, audience and influence' (Lundy, 2007). I question whether the *value* given to a disabled child and young person's 'voice' should be considered as an additional factor in the *support* available and the *regard* given to the child or young person's expressed voice by the ecosystems of disabled children and young people in England.

I conclude with a summary of the answers to the original research questions and draw together all the elements and factors into a conceptual framework of advocacy.

The sections of this chapter are as follows:

- 9.1 The Voice of children and young people – Support and regard through advocacy
- 9.2 Further consideration of the term 'Instruction'
- 9.3 Participation and other rights of children and young people
- 9.4 Advocate role as Observer, Conduit, Facilitator and Challenger
- 9.5 Value of children and young people rights of expression, support and regard
- 9.6 Drawing to a conclusion

9.1 The voice of children and young people– support and regard through advocacy

In the previous three chapters, a nuanced approach has been taken to explore participation through exploring the elements of ‘expression’, ‘support’ and ‘regard’. Participation in its totality and the role of the advocate in the realisation of participatory rights will now be drawn together.

In chapter five (expression), Figure 16 explained how the intention and means of the child or young person’s expression in communication was impacted by the context and crucially the receptivity of the receiver of the communication– namely the advocate. Throughout chapter five the advocates observation and skills, and their communication with others to find meaning was explored. In chapter six (support), the training, experience and understanding of legislation of the advocate was discussed. Figure 17 below hence adds the element of ‘training and experience’ in the dimension of ‘support’.

Regard for the child or young person’s expression was explored in chapter eight (regard). Regard by the advocate was highlighted, as well as the issues of regard for, within, from and despite, the ecosystem of the child or young person. The impact of expression, through support for the child or young person’s expression, does not just stop at the understanding of communication. It is taken on by both the advocate in future support and, through the advocate, to the ecosystem of the child or young person.

Figure 17 represents the relationship between the child or young person’s expression, and the support offered by an advocate, and crucially how the regard

for that expression influences the ecosystem and support given by the advocate. It is a dynamic relationship.

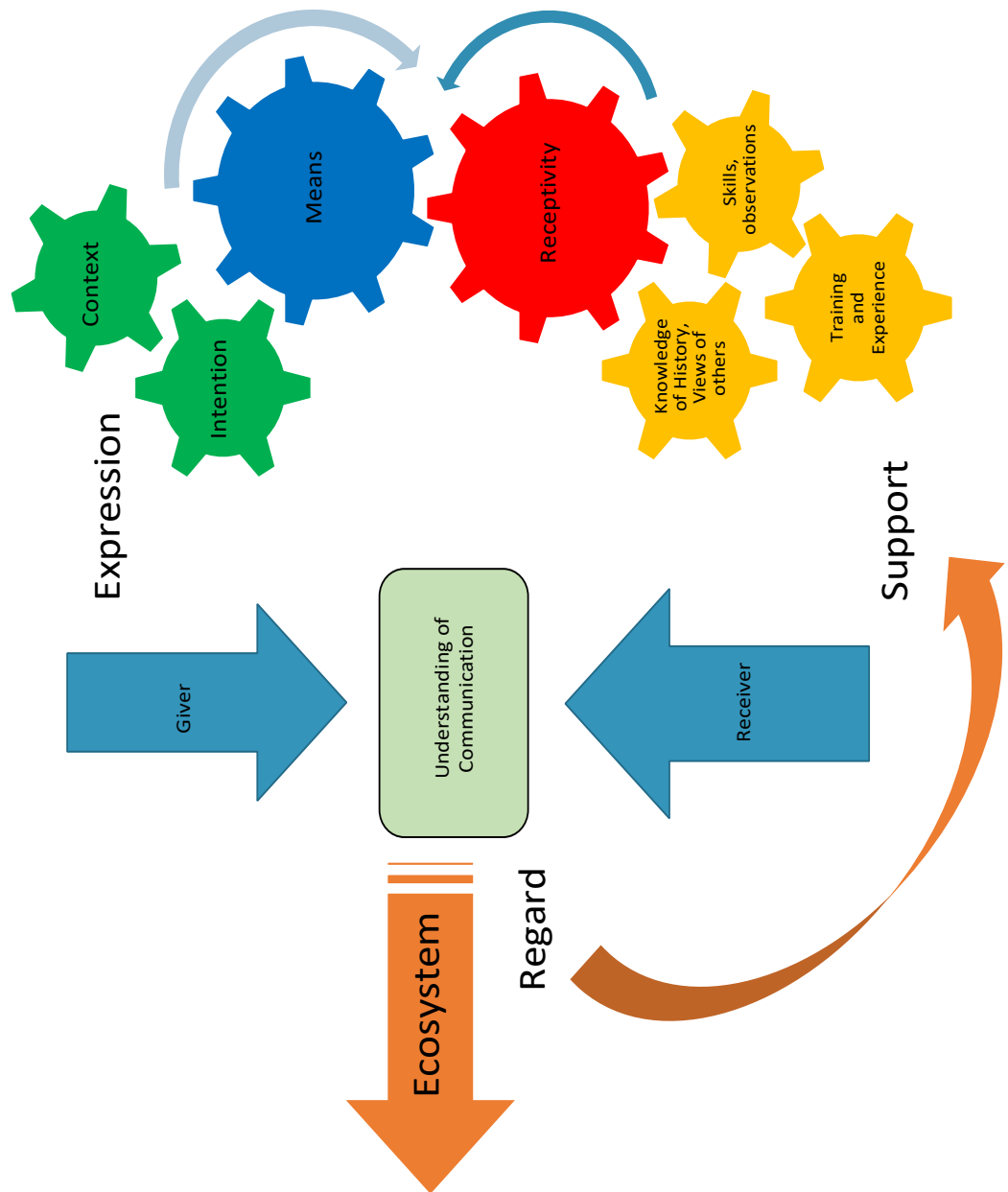


Figure 17: The dynamics and elements of expression, support and regard in participation

9.2 Further consideration of the term ‘Instruction’

In the previous chapter, I reflected on the term ‘non-instructed’ and suggested that advocacy should consider whether the binary term ‘non-instructed’ could be replaced by a term that better describes advocacy provision for people with complex communication needs that require specialist advocate support *on a continuum*.

Within this research, the children and young people in both the live cases and the fictitious vignette cases were described as ‘non-instructed’. Yet each child or young person evidenced a voice- a voice that was unique in the expression and support required. Every child or young person almost without exception demonstrated fluctuations in their communication within, and between, visits. The advocates themselves also contributed to the levels of interactions by the *purpose* of the visits. For example, Tobi’s advocate wanted to establish a rapport with Tobi on the first visit observed, but on the third visit, was keen to focus on observing Tobi and Tobi’s interaction with peers, and so Tobi’s advocate spent far less time interacting directly, but observed and spoke with carers and staff.

The *familiarity* of the advocate with the child or young person impacted on their ability to ‘tune-in’ to the child or young person communication. Whilst many advocates referred to gaining information about communication of the individual from others around, the advocates in the ‘live cases’ also gained information from the child or young person themselves as to their communication means and intent. Kim’s determination to put their crocs on to go outside, despite staff saying Kim would not be happy to do so, was read by the advocate as a way of Kim saying they were ok. Tobi’s advocate through observation established Tobi’s preference for peer interaction. The individual child or young person’s communication was picked up by the advocates because

they were able to draw on their experience of the individual's 'lived life' through observation and familiarity with the child or young person and thereby recognise the child or young person's agentic voice.

Diagram 9.2 shows the three dimensions of advocacy with people with complex communication needs. It draws on the three communication themes identified in literature and discussed in chapter two (literature) and in chapter six, seven and eight in relation to children and young people as communicators.

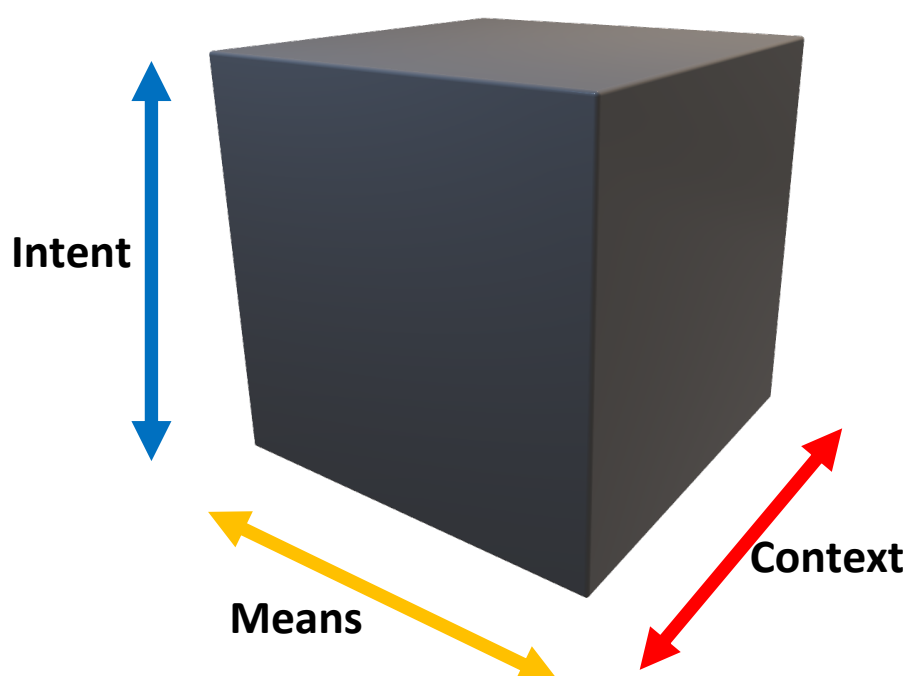


Figure 18 Cube of Instruction

Cube of 'instruction'

The 'cube of instruction' has three elements; means, intention and context:

Means (Hannon & Clift, 2013; Caldwell, 2012; Ogletree et al, 2011; Dan, 2008; Petry & Maes, 2006). This refers to the way in which communication is given. Such as:

- Gesticulation
- Facial
- Vocalisations
- Alertness
- Typical/ atypical for the individual

Intention: (Ogletree et al, 2011; Caldwell, 2012; Bunning, 2004; Grove et al, 2000). Intention can be indicated by the:

- Constancy- over time, in relation to secondary factors
- Definitiveness- degree of certainty or reactionary response

Context (Greathead et al, 2016; Solodiuk, 2013; Simmon and Watson, 2010; Bunning, 2004), other factors must be considered. These factors include:

- sensitivity to physical environment (light, noise, temperature)
- familiarity with advocate
- others around
- intended purpose of advocate visit

The receptivity to the child or young person's expression, as well as understanding the context and means for that child or young person's expression enables the advocate to have 'regard' for the child or young person's voice and agency and thereby respond accordingly. The eliciting of response by the child or young person; the child or young person's 'instruction', is facilitated through the advocate giving 'voice', 'space' and 'audience' to the child or young person's voice. The 'instruction' gleaned is on a continuum- the means of expression, the context and the intention of the child or young person. It is dynamic; it is multifaceted; it is also dependent on the advocates receptivity to the child or young person.

Whilst I would argue that the term ‘non-instructed’ could and should be abandoned, the issue foreseen with dispensing of the term ‘non-instructed’ is that *any* term that indicates a need for specialist advocacy provision may be counterproductive. Without a ‘label’, children and young people with complex communication needs may be ‘disabled’ by the lack of specialist communication tools or advocacy support. I consider that Wickenden’s argument for ‘strategic essentialism’ (Wickenden (2019, p 133) is applied to advocacy referrals. Whilst the tick-box’ of the binary term ‘non-instructed’ could be dispensed with, the referrer could be asked to clarify the communication means of the child or young person, thereby ensuring that appropriate support is forthcoming.

9.3 Participation and other rights of children and young people

The focus of this thesis has been on the *participation* of disabled children and young people with complex communication needs, through the support of independent advocacy. The ‘voice’ of the child or young person and the *support* and *regard* given to that *expression* through the ‘space, audience and influence’ (Lundy, 2007) offered through advocacy has been examined in the previous three chapters. Yet Lundy (2007) commends that elements of Article 12 should also be seen in context of the other articles. The articles of the UNCRC fall broadly into three focus areas; provision, protection and participation (Jones, 2011). Therefore, attention will turn briefly to how these rights are interconnected through the giving of ‘regard’ - space, audience and crucially ‘influence’, to the child or young person’s voice. Participation embedded in Article 12 UNCRC, can be seen as vital in providing insight from that young person into the issues surrounding their rights in protection and provision.

Negotiating, challenging or facilitating access and resourcing within education, health and social care were common issues for advocates across this research. As seen in the 'live cases', the regard for the child or young person's voice led advocates to advocate on behalf of the individual child or young person. For example; Kim's advocate in relation to specialist footwear, Rowan's advocate regarding the access to the iPad and Tobi's advocate around suitably trained and consistent staff in the classroom.

Rights of protection can also be impacted by rights of participation. Often the voices of disabled children and young people are marginalised in child protection issues (Franklin & Smeaton, 2016; Cossar et al, 2013), over and above the marginalisation of children and young people in general (Kennan, Brady & Forkan, 2017; MacDonald, 2017). The poor regard for disabled children and young people participation with suspected under-reporting and recording and lack of "space" and "voice" causes a negative spiral both in resourcing and protection issues. If support (through space and voice) was given and regard taken for the expression of these young people in the research and recording of incidences, then this would impact on future resourcing and protective services for others.

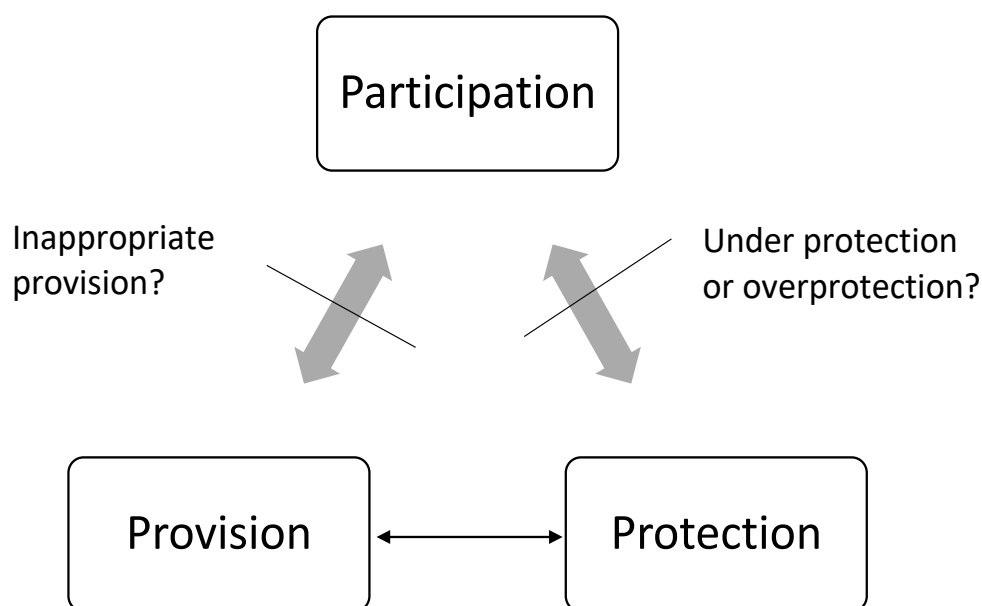


Figure 19: The impact on protection and provision through participation

To marginalise, ignore or overlook the voice of the disabled child or young person not only means Article 12 is not realised, but other rights of protection and provision will be impacted (MacDonald, 2017; Cossar et al, 2013). One conclusion drawn by advocates was that they believed *funding* influenced the breadth of choice of resources available for disabled children and young people and was setting the agenda, rather than the voices of the individual child or young person. The realisation of all rights for all children and young people does depend on the wider society acknowledging and facilitating those rights to be recognised. For disabled children and young people with complex communication needs, their ‘double vulnerabilities’ of being a child and having additional communication needs arguably is more impacted by the values of the society; to have regard for their voice and agency, and to provide the resources for that voice to be supported.

The advocate role in rights of provision and protection has not been explored fully in this thesis but is acknowledged as being of great significance. Further exploration is recommended.

9.4 Advocate role as Observer, Conduit, Facilitator and Challenger

Consideration will now turn to how advocates work. Much of the literature around advocacy for, and with, disabled children and young people has been focused on quantitative data around numbers accessing advocacy (Longfield, 2019; Longfield, 2016; Griesbach et al, 2012; DCELL Wales, 2011; Brady, 2011; Elsley, 2010), or on commenting on the lack of advocacy for disabled children

and people with complex communication needs (Longfield, 2019; Thomas et al, 2016; Brady, 2011; Franklin & Knight, 2011).

Whilst the “watching brief” tool is commonly used in ‘non-instructed advocacy’, and was cited by some advocates within this research, it is a series of rights and desirable outcomes (see Appendix 7) on which the advocate reports (notably, it was not designed specifically for children and young people). It does not describe the processes an advocate may use to find out the information on which to report. Research has rarely focused on the work of advocates, nor the processes involved or outcomes of advocacy. One of the aims of this research was to fill this gap in knowledge.

Within the previous three chapters, the role of the advocate in acting as an observer, conduit, facilitator and challenger has been raised. Throughout this thesis, I have used systems theory as a framework to examine the role of advocacy in the lives of disabled children and young people with complex communication needs. The children and young people as individuals have been focused on, but with the acknowledgement that they live within a community, family, society with legislation and policy, and therefore have an impact on, and are impacted by, their ecosystem.

The four distinct, yet related roles, and their place within the ecosystem of the child or young person, will now be explored.

Figure 20: The four roles of advocacy practice



The advocate as an Observer

All advocates within the live cases were seen to be observers of children or young people's expression; their 'voice', but also observers of the interactions of the individual in, and with, their surroundings. Tobi's advocate closely observed Tobi's reactions to peers, Sasha's advocate observed Sasha's behaviour of picking at the paint on the walls, for example. The majority of advocates interviewed spoke of the role of observation in their work as advocates.

Whilst observing may be seen as a passive activity to pick up very small indicators of communication, such as Kim's advocate observing Kim's 'non-reaction' when an upsetting incident was discussed, requires skill and understanding of communication. Advocates with experience of working with individuals with complex communication needs, particularly experience gained

before entering advocacy, were more confident in their ability to understand nuances of communication, particularly regarding behaviour. The training for advocates to observe *in detail*, and the support and supervision to explore the *meaning and context* of what they have observed, must be a consideration for advocacy agencies.

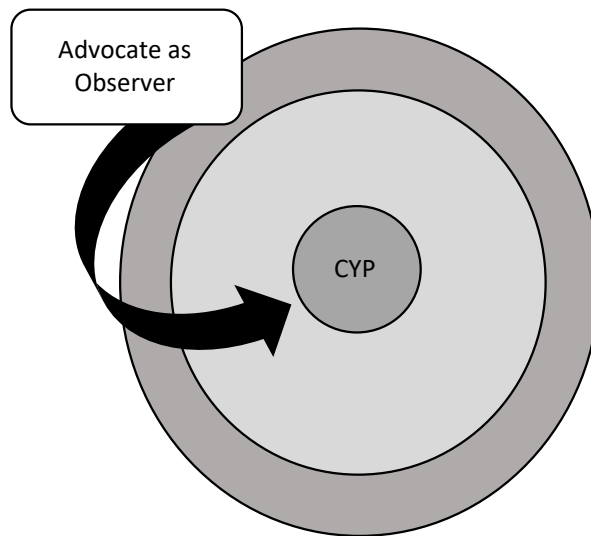
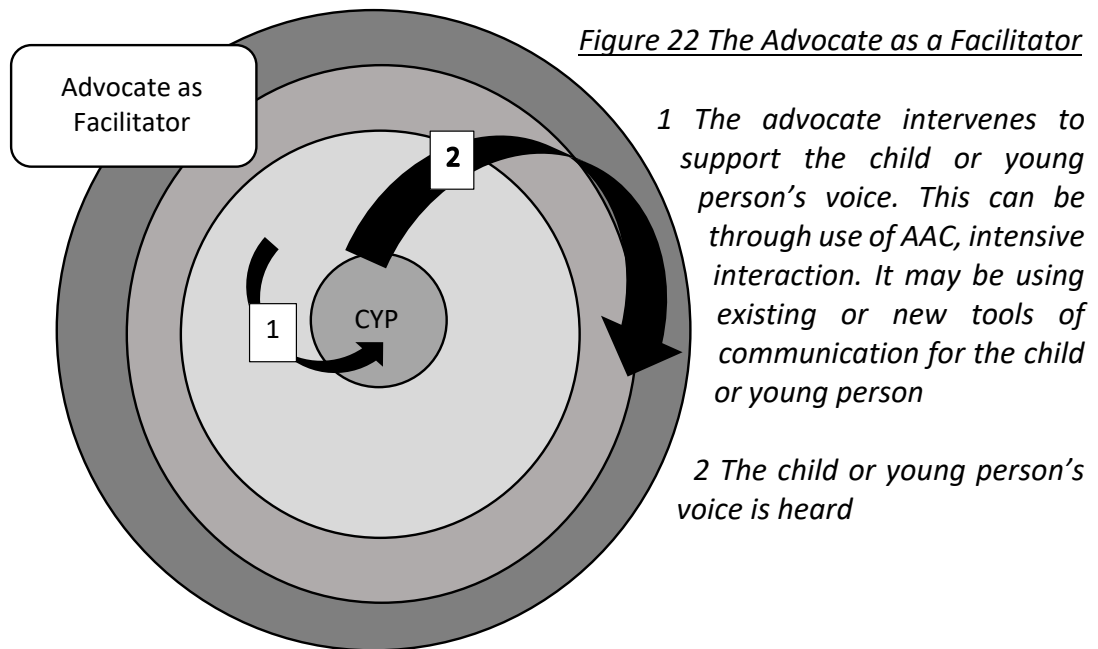


Figure 21: The Advocate as an Observer

As indicated in chapter six, to understand a child or young person's expression, observation needs time. Time in length of observation, time to repeat observations, and time to observe at different times a day and environmental settings. Attention to detail and noting small changes are important. Being an observer as an advocate is essential to understand the expression of the child or young person's lived experience; their individual 'voice'. I would argue that being an observer is essential as an advocate for even the most articulate individual as non-verbal communication transmits more meaning than verbal communication (Ross, 2012; Bunning, 2004).

The Advocate as a Facilitator



Being a facilitator is a more active role, in that it requires action and interaction with the child or young person, in order to establish a greater sense of meaning for that child or young person's voice. It is very significant in the giving of 'space' and 'audience' to 'voice'. However, in order to facilitate the child or young person's voice, appropriate means of interaction need to be utilised. Advocates across the study reported that sometimes they felt they lacked the skills and training to be able to interact with disabled children and young people appropriately. This should be of great concern.

As with advocates acting purely in the role of observers, advocates acting as facilitators of voice, may not in itself support the child or young person's voice to be heard and be 'regarded' by the ecosystem of the child or young person. Nevertheless, advocates demonstrated that their role as facilitator was often in the context of the ecosystem, in that they relied on information about the individual's communication from the meso-system. Tools to facilitate

communication with the child or young person were at times as a result of advocates challenging the ecosystem to provide the necessary resources to support the child or young person's voice. Whether this be through the use of PEC's with Tobi, or the use of iPad with Rowan.

The Advocate as a Conduit

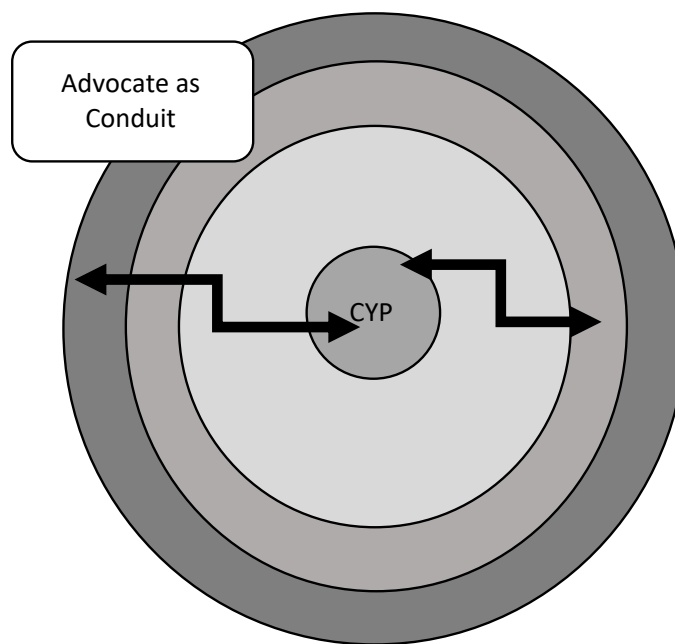


Figure 23 Advocate as a Conduit

When an advocate facilitates communication, which is in turn communicated to others within the ecosystem, the advocate works as a conduit. When considering the development of advocacy as independent from other professions, the overriding principle was that of *representing* a person's views (Brandon & Brandon, 2001; Henderson & Pochin, 2001). The role of advocates is as a channel for the person's wishes and feelings to be heard by others. Within the live cases, advocates often acted as conduits for the voice of the child or young person they were working with. Being an observer and/or facilitator is a pre-requisite for the role as a conduit. Without giving 'space' and 'audience' and recognising the child or young person's 'voice', the advocate cannot act a conduit for that voice.

The stimulus of the Billy vignette led advocates to describe their role in disseminating information to the children and young people with whom they work. The role of an advocate is not to *replace* the communication of other professionals to a child or young person, but to support both the child or young person and a professional to understand the communication of the other.

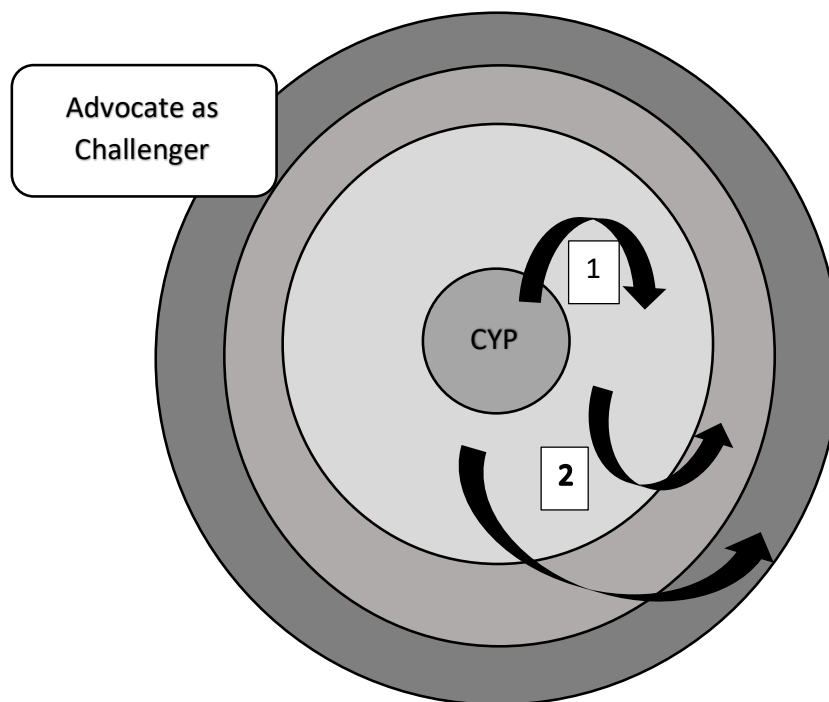
The Advocate as a Challenger

The role of an advocate as a ‘challenger’ for the rights of the people they are working with is not a new concept. Historically the term ‘advocate’ is to represent and to challenge “*effectively pressing their case to influence others.*” (Brandon & Brandon, 2011, p. 20):

Taking action to help people say what they want, secure their rights, represent their interests and obtain the services they need”. (from Action for Advocacy Macadam et al 2013, p. 4)

Within the ‘live cases, advocates challenged for the rights of children and young people and many of the interviewed advocates also demonstrated their role in challenging others for Shabnam’s rights to dignity and confidentiality, and for Billy to have choices in her care.

One of the issues for advocacy practice impacting on the effective challenging of children and young people's rights highlighted by this research, has been the training and knowledge of legislation of advocates. Without sufficient knowledge of legislation surrounding children's rights of participation, protection and provision, it is questionable how an advocate can credibly challenge. Advocacy does not have the professional status of nursing or social work, and this “non-professional” role can lead to issues of confidence for advocates (Forbat & Atkinson, 2005). Particularly for children and young people with complex communication needs, the lack of ‘professionalism’ in intensive training of communication and understanding of legislation can lead to ineffective practice.



*Figure 24:
The Advocate
as Challenger*

1. Advocate receives instruction through observation or facilitation
2. Advocate challenges the ecosystem to take regard, uphold rights of children and young people

In order for advocates to challenge for the rights of the disabled children and young people they work with, there has to be the provision of advocacy in the first place. Whilst there is legislation for advocacy, this does not have the breadth or depth to ensure that all children and young people with complex communication needs can have the specialist support through independent advocacy. Independent advocacy does not undermine the role of parents in advocating, nor the important role of professionals advocating within their realms of practice (Boylan & Dalrymple, 2009). Although independent advocacy would ideally be completely “independent”, in reality, advocates are still working within the realms of the commissioning service itself. Regard for children and young people’s voice may become negated by the relationships with institutions and contract commissioners.

Advocacy, in the sense of standing up for the rights of others has been the legacy of humanity's past, and so advocacy will need to continue whilst human vulnerabilities and inequalities exist. However political will to *fund* advocacy to enable voice, choice and human rights to be upheld may be a challenge to this, particularly for children and young people not covered under current legislation. Whilst peer and collective self-advocacy continues, funding for non-statutory advocacy services is being squeezed. The challenge facing advocacy is to balance the evidence of provision for funding through proven outcomes, whilst maintaining the voice of the child or young person and where necessary challenging society provision and attitudes.

9.5 Value of children and young people's rights of expression, support and regard

Throughout this thesis I have used systems theory as a theoretical framework to examine advocacy and its place in the realisation of rights of disabled children and young people with complex communication needs as unique and individual people. The microsystem of the child or young person /advocate relationship was considered within the context of the meso-system, and how this in turn impacts, and is impacted by, the macro system; the wider political, social and community context of the child or young person. The chrono-system has not been highlighted significantly through this thesis. However, I consider that the underlying values and perceptions of both childhood and disability to be significant in the realisation of disabled children's rights.

In the background literature (chapter one and two and three), the concepts of childhood, rights and the realisation of rights by disabled children and young

people was considered. Whilst there has been a shift in perceptions of disability, from the medical to social model (Oliver, 2013; Shakespeare & Watson, 1997), and from viewing children as passive recipients to having ‘agency’ (James and Prout, 1997; Qvortrup, 1994), *disabled children* are still more vulnerable and less visible and recognised as having ‘agency’ than their non-disabled peers (Browne & Millar, 2016; Tisdall, 2012). Discrimination and ‘othering’ of disabled children and young people has been condemned yet evidence persists (Brady & Franklin, 2019; Liddiard et al, 2019; Longfield, 2017; Curran and Runswick-Cole, 2013).

The UNCRC and the UNRPD are very clear that rights are *without discrimination*. Nevertheless, the review of the evidence of provision of advocacy in the UK (chapter five), exposed that even when provision is made for children and young people participation through advocacy, access and provision for *disabled* children and young people particularly with complex communication needs (‘non-instructed’) is substantially less than non-disabled peers (Longfield, 2019; Baillie, 2015; Selwyn, 2013; OFSTED, 2012; Elsley, 2010). Even when advocacy is provided, there is some evidence that advocate training and support may be inadequate (Longfield, 2019; Taylor et al, 2015; Franklin & Knight, 2011; Brady, 2011; Elsley, 2010).

The reports of advocates themselves (chapters six, seven and eight), support the evidence from other sources that the voices of disabled children and young people, defined as the expression of lived experience in which their wishes and feelings may be conveyed, are not valued equally to their ‘non-disabled’ peers. Lundy’s factors of voice, space, audience and influence (Lundy, 2007) have been instrumental in understanding that Article 12 regarding participation does not ‘just happen’. It is recognised that ‘influence’ is often a sticking point for any child's participation (MacDonald, 2017; Lewis, 2010). The infantilization of disabled children and young people, and the failure to see them as ‘social agents’ but rather as ‘others’ remains (Wickenden, 2019; Stafford, 2017; Goodley & Runswick-Cole, 2014; Tisdall, 2012)

Figure 25 demonstrates again the relationship between Lundy's factors of 'voice audience, space and influence', in relation to the UNCRC Article 12 elements of *expression, support and regard*. Regard for the expression of a child or young person with complex communication is questionable and subject to the *value* placed on their 'voice'. Figure 1 in chapter 2 included the element of 'value'. The giving of value by society to the voice of disabled children and young people with complex communication needs can only be questioned by the evidence of this thesis. I assert that value to the expression, support and regard for the child or young person's participation is *all encompassing*. Value determines the acknowledgment of a child or young person's expression as the recognition of 'voice' as the articulation of the individual's lived experience. Value of a disabled child or young person's voice means that adequate provision is made to ensure the 'space' through support, and crucially, value of the child or young person's voice ensures that there is 'audience' and 'influence' without prejudice to their agentic voice.

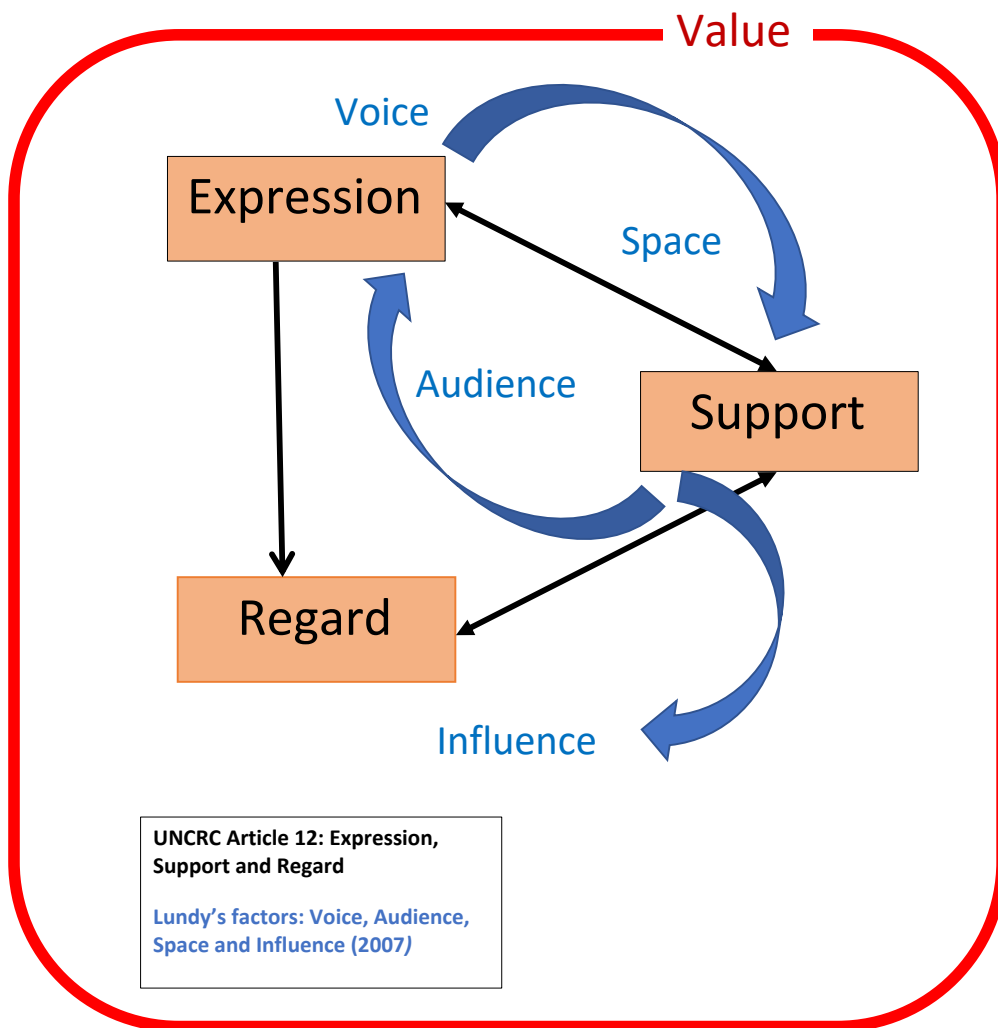


Figure 25: The relationship between Article 12, Lundy's factors and value for the participation of disabled children and young people

It is within this relationship that advocates work. Whilst advocates are often working with limited resources and time, some with little experience or training, the fact that they are doing the job they are doing is heartening. Support by the macro system through better funding for resources and training, and the recognition of the important role that advocates play, may go some way to demonstrate more 'valuing' of the voice of disabled children and young people.

One advocate summarised advocacy thus:

Advocacy is giving the most vulnerable people a voice. It not about stating an opinion, it's about holding services accountable for decisions that they make. And showing not just the professionals involved, but everyone around that person that actually we do respect this person as an individual, we do value them... just because somebody can't speak or can't point at a picture, doesn't mean that they are any less of a person, and they have rights just like anyone else does. AX

It is this with this insight I bring my research to a conclusion.

9.6 Drawing to a conclusion

In the above sections I have pulled together the strands of the findings and discussions of the previous chapters and set out core features of advocacy practice, with the voice of disabled children and young people being central to this.

The aims of this research were to:

- To gain a deeper understanding of the use of advocacy as a mechanism for ensuring that the views of disabled children and young people are central to decision-making about their lives.
- To understand and examine the evidence for, and practice of, what is currently termed “non-instructed” advocacy with disabled children and young people.
- To develop a conceptual framework of advocacy in order to advance future effective advocacy practice with children and young people with complex communication needs.

In the introduction to this thesis I set out four key questions as a guide to fulfil the aims of the research. I will now recap on my findings and discussions to demonstrate how my research has answered the questions.

What is the evidence of advocacy practice in this country for disabled children and young people with complex communication needs?

Advocacy with disabled children and young people with complex communication needs is evident in literature inasmuch as its existence is acknowledged. It is clear access and provision of specialist advocacy is patchy and inconsistent across the country, despite previous research recommending that advocacy for disabled children and young people should be improved. Much of the evidence from literature concerns the provision and access to advocacy, not the processes and the advocacy relationship itself.

The fieldwork, particularly the ethnographic study, provided rich data evidencing the practice of advocacy with in the microlevel of the child or young person-advocate relationship. This is a significant contribution to research in this field of advocacy with disabled children and young people with complex communication needs, which up to now has been minimal.

What does 'non-instructed' advocacy mean? Is it an appropriate term for advocacy with disabled children and young people with complex communication needs?

Whilst the Children's Commissioner for England has defined non-instructed advocacy, the literature evidence and the evidence from advocates themselves

demonstrates that the meaning of 'non-instructed' advocacy is ambiguous and not necessarily a familiar term for other professionals.

I argued that the term 'non-instructed' is unhelpful and misleading, and therefore not an appropriate term if the aim of advocacy is to be truly person-centred and working *with* a person rather than *for* a person. Non-instructed implies that the person is non-participatory. I consider that the binary nature of the term 'non' impacts on both advocate and others around the child or young person regarding expectations and limitations of the child or young person's expression. Advocacy is a tool for support. If advocates are trained, experienced and skilled in understanding and facilitating non-verbal communication, a degree of 'instruction' may be possible through regarding the voice of the child or young person. I believe that advocacy is better described on the continuum referencing communication. Therefore, 'non-instructed' could be re-termed 'advocacy for people with complex communication needs that require specialist support'.

In my conclusions, I proposed a 'cube of instruction', which takes into account a child or young person's means of expression, the level of intention, and also the context. However, I also recognise that the term 'non-instructed' has been coined because a significant role of advocacy is to uphold the rights of people advocates work with (Brandon & Brandon, 2001; Henderson and Pochin, 2001; Macadam et al, 2013) and that there is a recognition that the person they are working with may not be aware of or understand their rights; they would therefore be unable to 'instruct'. Nevertheless, in advocacy practice, the majority of people using the services do not, certainly at first, know or understand all their rights. Again, the recognition and understanding of an individual person to enact their rights could also be regarded on a continuum.

Does advocacy enable 'voice' for disabled children and young people with complex communication needs? If so, how?

The short answer to this question is yes, advocacy does enable voice for disabled children and young people with complex communication needs. However, there are many factors in the effective enabling of 'voice'.

Advocacy can facilitate 'voice' through receptivity to a child or young person's means and intent of communication and by the advocate awareness of the context of the communication. Advocates interact with the meso-level of the child or young person's ecosystem in order to understand their typical/atypical communication. However, advocates can find it challenging to maintain independence of judgement and remain child or young person focused.

Advocates have four distinct roles in supporting the 'voice' of children and young people to have 'space, audience and influence' (Lundy, 2007), by being an *observer* of expression, a *facilitator* of expression, and a *conduit* and a *challenger* to the ecosystem to have regard for the voice of the child or young person.

What factors impact upon independent advocacy practice with children and young people with complex communication needs?

There are many impacts on the practice of advocacy with children and young people with complex communication needs. On the micro-level of the advocacy interaction between the child or young person and their advocate may be influenced by the skills of the advocate to thoroughly hear and make sense of the child or young person's agentic voice, and the knowledge to act and uphold rights within their wider eco-system.

The context may be significant. For example, time of day, other people around, the temperature of the room and the wellness of the child or young person themselves. The advocate has to be receptive to the communication of the child or young person, and able to manage the relationships with people working with and around the child or young person. This study has demonstrated that advocates with skills and experience of communicating with disabled people/people with Learning Disabilities, and advocates who are trained and knowledgeable of the rights of children and young people, are able to impact positively to actuate the rights of participation for the children and young people they work with.

Parents and professionals can be both positive and negative gatekeepers to access for children and young people to advocacy. Parents in this study were supportive of independent advocacy for their child. The children and young people of this study were clearly accessing advocacy but advocates across the study spoke of their concerns particularly around residential advocacy and statutory advocacy provision for out-of-area residential care. The findings of the fieldwork confirmed the findings of literature suggesting that access, provision and funding for advocacy, particularly for disabled children and young people, is inconsistent in this country.

The exposing of the factors impacting on independent advocacy practice suggest there are several issues for future policy and practice to consider. These will be outlined in the conclusion of this thesis in considering challenges and opportunities afforded by the results of this research.

9.7 The framework

In answering the questions, I have been able to draw together the elements and factors of advocacy practice. This chapter was titled: “Realisation of children and young people’s rights; towards a framework of practice for advocates “. Working towards a framework of advocacy was one of the three aims of this thesis, built on the evidence of advocacy practice gleaned. Figure 26 is my conceptualisation of advocacy for children and young people, particularly children and young people with complex communication needs requiring specialist support. The four areas of the conceptual framework are *relationship*, *practice*, *purpose* and *context* of advocacy.

The *practice* of advocacy as an observer, facilitator, conduit and challenger has the *purpose* of ensuring that rights of children and young people are upheld, in particular in the support of children and young people's voices in decision-making under Article 12 of the UNCRC. The fulfilment of the *purpose* of advocacy is practised in the *context* of the ecosystem of the child or young person. The meso system of the child or young person's family, education, health and care are impacted by legislation, policy and funding as well as a culture and community surrounding the child or young person. Whilst the advocate works within the context of the child or young person and often relies on the input of family, carers and professionals around the individual to discover wishes and feelings, likes and dislikes, the *relationship* with the child or young person is central to advocacy practice.

The relationship of the advocate and the child or young person is dynamic, and the skills, knowledge and values of the advocate facilitate the individual's expression to be supported and regarded. Thus, the advocacy *relationship* is *practiced* in the *context* of the child or young person's ecosystem to fulfil the *purpose*. However, whilst the UNCRC and the UNCRPD set out rights, the enactment of those rights on a local, national or international level

are not guaranteed. Advocacy practice can impact upon, and be impacted by, the context of the advocacy relationship and the value placed on the 'voices' of disabled children and young people. The relationship, practice, context and purpose of advocacy are interlinked.

This conceptual framework is not definitive; I intend for it to be used and discussed by advocacy practitioners in the hope that it will impact positively on future practice and policy.

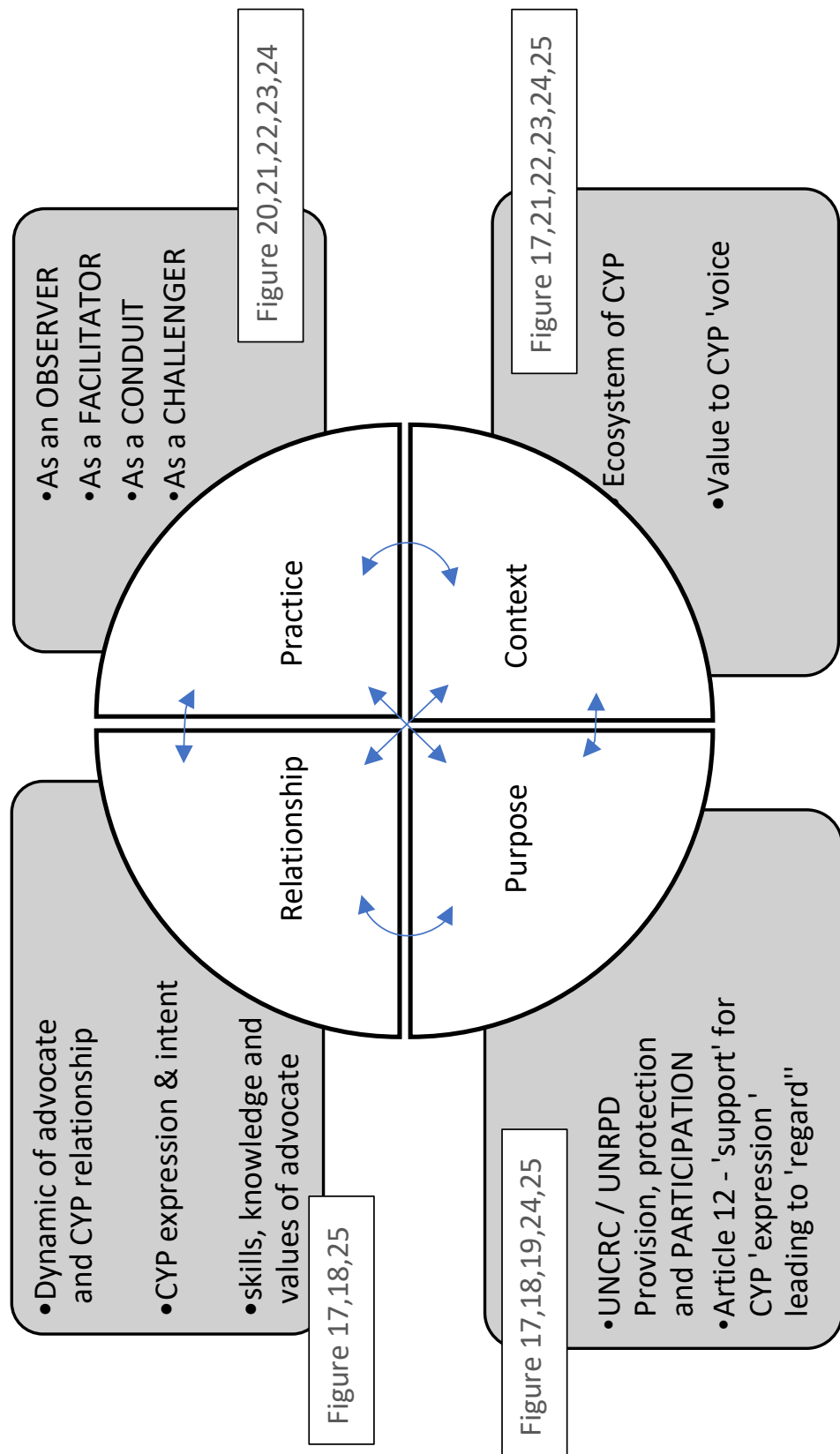


Figure 26: Conceptual framework of advocacy

Conclusion of Thesis

Summary

This thesis has focused on the use of independent advocacy as a tool to support children and young people with complex communication needs in decision-making, a right afforded under Article 12 of the UNCRC.

In order to examine the wider picture of advocacy provision for disabled children and young people in this country, I conducted a literature review of research, policy documents and reports relevant to advocacy and disabled children and young people within the UK. I also conducted an ethnographical study of five children and young people receiving advocacy support with their advocates, and held eleven semi-structured interviews, using vignettes to replicate cases, with advocates with 'non-instructed' advocacy experience.

The results of the literature search, the case studies and the interviews has enabled a deeper understanding of advocacy provision in the UK. This research has been innovative in examining in detail the advocacy relationship between the child and young person and their advocate. I used the elements of Article 12; namely *expression*, *support* and *regard*, to explore the advocacy relationship with disabled children and young people with complex communication needs accessing what is termed 'non-instructed' advocacy. Using systems theory (Bronfenbrenner, 1979) I examined this micro relationship of the advocate and child or young person within the context of the family and health, education and social care systems. Lundy's four factors of space, voice, audience and influence were also considered, and I added an additional factor of 'value'. Evidence indicates that 'valuing a child or young person and their 'voice' impacts on the

‘support’ and ‘regard’ given to that voice from the child or young person ecosystem.

I question whether the term ‘non-instructed’ is an appropriate term for advocacy for children and young people with complex communication needs. Such a term implies a binary notion of ‘having not’, yet through analysis of data, I argue that advocates take instruction in their regard for the voice of children and young people, expressed through vocalisations, gesture, body language and behaviours. I contest that means and intention of expression, and therefore instruction, are on a continuum and suggest that ‘non-instructed advocacy’ be re-termed ‘advocacy for people with complex communication needs that require specialist support’.

I suggest a ‘cube of instruction’ to aid advocates to consider means, level of intention and the context of communication and to facilitate the individual agency and voice of the child or young person . Whilst advocacy for children and young people with complex communication needs can play a significant role in the rights of *participation* afforded by UNCRC Article 12, The UNCRC also affords rights of *provision* and *protection*. Advocacy for disabled children with complex communication needs may therefore also take the form a ‘guardian of rights’ to hear the voice of a child or young person as the *expression of their lived lives* and act to support and ensure that their rights of provision and protection are upheld within ecosystem of the child or young person .

I conclude that advocates have a fourfold role of *observer, conduit, facilitator and challenger* within the ecosystem of children and young people and in the realisation of the rights of children and young people, particularly those with complex communication needs.

Limitations of study

This research is limited by the small number of children and young people directly involved in this research. None of the children or young people were perlocutionary communicators. Whilst I argue that the evidence is rich and insightful into the advocacy relationship with the five children and young people of this study and all children and young people are unique, the evidence could have become more validated if there was a wider range and greater number of children and young people. Nevertheless, the added input of advocates experiences of cases gleaned from the vignettes, helped to mitigate some of this limitation. However, from an advocate point of view, not, as I had initially wanted, from the child or young person's view.

The experiences, training and knowledge of advocates interviewed varied tremendously. Whilst this could be indicative of advocacy across the country, I am reluctant to draw too many conclusions, particularly as vignettes are not 'real-life' situations.

Geographically, the fieldwork was conducted within England, although the literature review covered the UK and one advocate also worked in both England and Wales. Legislation is different across the regions of the UK. But, as seen within the literature and fieldwork of this study there are real differences between application of legislation and policy in respect of access and availability of advocacy services *between* England's local authorities. I am aware therefore that there are possibly many children and young people for whom advocacy could be a vital tool, but for whom there is no provision as yet.

I am very grateful to the parents of the children and young people in this study to give permission for me to carry out this research with their children. But I am also aware that these were cases where the local authority held 'parental responsibility' and I was not able to obtain the necessary permissions.

Challenges and opportunities

This research raises many questions for advocacy in particular for children and young people with complex communication needs.

For further research

This research was limited by the length of study. Longitudinal studies of children and young people accessing advocacy could provide more evidence of the impact of the advocacy relationship for the voice of the child or young person over time.

A point raised by advocates themselves when considering the Shabnam vignette, was the under referral from BAME communities. All the advocates within this research were white British. There were no speakers of other community languages, and no advocate declared a disability. Whilst I am aware that advocacy agencies are trying to be as diverse and representative of the communities they support, low referral rates from the BAME community may be something to consider with BAME communities themselves.

Parents acting as advocates has been researched, but the relationship between parents and advocates has not in-depth. Parents supporting their child in accessing independent advocacy has not been considered by researchers thus far, but particularly with young people with complex communication needs, the input of parents can be invaluable. Within this research, advocates cited parents in both positive and negative terms and as gatekeepers to their children accessing advocacy. Parents were also consulted and asked about their opinions on advocacy. Whilst the focus of this research was children and young people, it is evident that many parents carry a burden of advocating for their child. As young people approach adulthood, rights and responsibilities change and advocacy services may become more involved as a result of legislation such as the Care Act 2014 and the Mental Capacity Act 2005. Possible research with

parents themselves could also impact on advocacy for children and young people whose parents are not able to support their children, or who are reluctant for their child to access support.

A more critical and in-depth study into the training and experiences of advocates may be beneficial in developing better tools for advocacy, particularly with people with complex communication needs.

For advocacy agencies

The training and support of other professionals to understand advocacy as a unique tool for supporting a child's voice may improve referral rates for disabled children with complex communication needs. However, this is dependent on firstly sufficient funding to be able to provide the service and secondly, the ability of advocacy agencies to provide a high-quality advocacy service. Whilst this study did not aim to comment on the quality of advocacy, it was clear that the experiences of advocates before they started their post had an impact on their confidence and perceived skills in communicating with children and young people with complex communication needs. Training, particularly in communicating with, and understanding of, children and young people with complex communication needs can only be beneficial. Most advocates in this study felt they lacked the skills and training to be effective in facilitating a child or young person's communication, although the advocates in the 'live-case' were often effective despite their concerns.

In addition, advocates in their role as challenger within the ecosystems of children and young people, would benefit from a deep understanding of children and young people's rights and their rights under legislation from birth into adulthood. As indicated, many advocates did not know relevant legislation to the vignette cases.

For consideration by policy makers

The findings of this study raise concerns around the issues of commissioning services. Firstly, in regard to advocacy for children and young people placed 'out of the area' accessing residential advocacy support. There appears to be inconsistent advocacy support around statutory issues because of the limitations of the commissioned service and communication with the funding local authorities. A consistent approach between funding authorities, settings and local authorities in which the setting is, could avoid issues of children and young people falling between the gaps in advocacy provision. Independent advocacy has to be priority for children and young people who, by virtue of their communication needs and reasons why they are in residential care, are vulnerable and need support of independent advocacy to reduce the risk of further scandals such as Medway and Winterbourne. However, funding is contentious and linked to the second issue of commissioning services. Fears of 'rocking the boat', particularly if it means challenging the commissioning body, may impact on the effectiveness of the advocate role. Whilst it is understood that advocates should be diplomatic, they have a role in challenging for the rights of children and young people.

Of great concern was the disparities in the commissioning of services per se, a point raised by the Children's Commissioner in her recent report (Longfield, 2019). Consistent commissioning and application of legislation and policy *must* be possible. But it will be beholden to the willingness of funding agencies and policy enforcers, to make this happen.

Disabled children and young people with complex communication needs are often the bottom of the pile when it comes to resourcing (Longfield, 2019; Longfield 2017; Pinney, 2017). Advocacy not only has a role in individual lives, but in collectively advocating for the rights of children and young people to be upheld. I do question the value given to the voice of children and young people

with complex communication needs within our society. One of the biggest challenges of advocacy therefore is to raise the profile and challenge societal attitudes to disability, and to the rights of children and young people with complex communication needs.

Singing for Eddie

I can only surmise that if my cousin Eddie was a young child now, at least some of the issues and challenges that faced my aunt and uncle, and Eddie, could have been lessened by accessing appropriate services and support. Certainly, if he went away, and if he was to access advocacy support, I hope that Eddie would not be assaulted, or at the very least, be provided with specialist support to aid his recovery. I would hope he would not lose so much weight or be moved without good reason. I also would hope he could be placed close to his mum. Sadly, I know that not all these hopes for Eddie would be a reality, even today.

If Eddie was still the young man I remember, I would like to think that Eddie would have had an advocate. I hope they would have got to know this tall, dark-haired young man who could not sit still; this anxious young man who had a bag he persistently carried around, with a picture of his nanna inside along with several carefully wrapped up cars. This advocate would have observed and taken note when Eddie startled and screwed his face up when the door banged on the wall, and then asked questions of staff and suggested things like - replacing 'that' missing doorstep. This advocate would have noticed Eddie responding to quiet talking; they would have taken time to stand alongside Eddie as he looked out of the window, and learnt that Eddie wanted to be outside, rain or shine. I would like to think that this advocate would have found out about my aunt visiting, and how important singing is to Eddie, and exactly what songs calmed Eddie.

Advocacy cannot 'fix', but it can listen and support to understand; it can regard; it can facilitate voices and challenge others to listen to those voices...and find the right songs to sing.

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Appendices

Appendix 1 i Research Ethics Review Checklist

FORM UPR16

Research Ethics Review Checklist

Please include this completed form as an appendix to your thesis (see the Research Degrees Operational Handbook for more information)



Postgraduate Research Student (PGRS) Information		Student ID:	961514
PGRS Name:	Jo Miriam Greenaway-Clarke		
Department:	FHSS	First Supervisor:	Professor Anita Franklin
Start Date: (or progression date for Prof Doc students)	September 2016 (Coventry University) transferred Oct 2019		
Study Mode and Route:	Part-time <input type="checkbox"/> Full-time <input checked="" type="checkbox"/>	MPhil <input type="checkbox"/> PhD <input type="checkbox"/>	MD <input type="checkbox"/> Professional Doctorate <input type="checkbox"/>
Title of Thesis:	Advocacy and 'Non-Instructed' Advocacy with Disabled Children and Young People with Complex Communication Needs		
Thesis Word Count: (excluding ancillary data)	73338		
<p>If you are unsure about any of the following, please contact the local representative on your Faculty Ethics Committee for advice. Please note that it is your responsibility to follow the University's Ethics Policy and any relevant University, academic or professional guidelines in the conduct of your study</p> <p>Although the Ethics Committee may have given your study a favourable opinion, the final responsibility for the ethical conduct of this work lies with the researcher(s).</p>			
UKRIO Finished Research Checklist: (If you would like to know more about the checklist, please see your Faculty or Departmental Ethics Committee rep or see the online version of the full checklist at: http://www.ukrio.org/what-we-do/code-of-practice-for-research/)			
a) Have all of your research and findings been reported accurately, honestly and within a reasonable time frame?	YES	NO	<input checked="" type="checkbox"/>
b) Have all contributions to knowledge been acknowledged?	YES	NO	<input checked="" type="checkbox"/>
c) Have you complied with all agreements relating to intellectual property, publication and authorship?	YES	NO	<input checked="" type="checkbox"/>
d) Has your research data been retained in a secure and accessible form and will it remain so for the required duration?	YES	NO	<input checked="" type="checkbox"/>
e) Does your research comply with all legal, ethical, and contractual requirements?	YES	NO	<input checked="" type="checkbox"/>
Candidate Statement:			
I have considered the ethical dimensions of the above named research project, and have successfully obtained the necessary ethical approval(s)			
Ethical review number(s) from Faculty Ethics Committee (or from NRES/SCREC):	CU FHSS	P55267 2019-075	
If you have <i>not</i> submitted your work for ethical review, and/or you have answered 'No' to one or more of questions a) to e), please explain below why this is so:			
Signed (PGRS):			Date: 30.06.20



Certificate of Ethical Approval

Applicant:

Jo Greenaway

Project Title:

The Conceptualisation and Application of Advocacy and "Non-Instructed" Advocacy
with Children and Young People with Complex Communication Needs.

This is to certify that the above named applicant has completed the Coventry
University Ethical Approval process and their project has been confirmed and
approved as High Risk

Date of approval:

21 July 2017

Project Reference Number:

P52267

Amendments and ethics and supplements P52267

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Dear Jo

Thank you for your amendment request. We can confirm the reviewer has approved the changes which will now be uploaded to your application.

Many thanks,
HLS Ethics

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Appendix 1 iv Sponsor Letter

TO WHOM IT MAY CONCERN

QRS/Ethics/Sponsorlet

Friday, 21 July 2017

Dear Sir/Madam

Researcher's name: Jo Greenaway
Project Reference: P52267
Project Title: The Conceptualisation and Application of Advocacy and "Non-Instructed" Advocacy with Children and Young People with Complex Communication Needs.

The above named researcher has successfully completed the Coventry University Ethical Approval process and received authorisation for their project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this researcher and attach details of our Public Liability Insurance.

Yours faithfully



Olivier Sparagano
Associate Pro-Vice-Chancellor – Research

Enc

Appendix 1 v Evidence of adoption by University of Portsmouth



Professor Matthew Weait,
BA (Hons) MA MPhil DPhil FAcSS
Professor of Law and Society
Dean of the Faculty of Humanities and
Social Sciences

T +44 (0)23 9284 6012
E matthew.weait@port.ac.uk

Faculty of Humanities and Social
Sciences
Park Building
King Henry I Street
Portsmouth PO1 2DZ

T: +44 (0)23 9284 8484
port.ac.uk/fhss

FAVOURABLE ETHICAL OPINION

Name: Jo Greenaway

Study Title: The Conceptualisation and Application of Advocacy and "NonInstructed" Advocacy with Children and Young People with Complex Communication Needs.

Reference Number: FHSS 2019-075

Date: 18/12/2019

Thank you for submitting your amended application to the FHSS Ethics Committee, and approval from Coventry University.

I am pleased to inform you that FHSS Ethics Committee was content to grant a favourable ethical opinion of the above research on the basis described in the submitted documents listed at Annex A, and subject to standard general conditions (*See Annex B*).

Please note that the favourable opinion of FHSS Ethics Committee does not grant permission or approval to undertake the research/ work. Management permission or approval must be obtained from any host organisation, including the University of Portsmouth or supervisor, prior to the start of the study.

Wishing you every success in your research

A handwritten signature in black ink, appearing to read 'Mr Richard Hitchcock', on a light-colored background.

Chair

Mr Richard Hitchcock

Email: ethics-fhss@port.ac.uk

Annexes

A - Documents reviewed

B - After ethical review

ANNEX A - Documents reviewed

The documents ethically reviewed for this application

<i>Document</i>	<i>Version</i>	<i>Date</i>
Ethics Application Amendment Request forms	N/A	N/A

Appendix 2 Ethnographic study- Information and Consent

Appendix 2i Sample Information for settings and local authorities

Children and Families Research
Faculty of Health & Life Sciences
Coventry University
Priory Street
CV1 5FB



(Insert Date)

Dear (SW name)

My name is Jo Greenaway and I am wishing to conduct research for my PhD at Coventry University.

My research will be looking at advocacy and 'non-instructed' advocacy for children and young people with complex communication needs. I am observing the work of XXXXXXXX from XXXXX with whom I have also gained approval and consent to research.

I am proposing to visit with the advocate (Advocate name) and observe the advocacy work and interaction with the child/young people with whom the advocate works. Individual consent for a child or young person to participate will be sought from the parents or guardians of the child/young person. In addition, each young person or child for whom permission by parent/carer/Responsible Person has been granted, will have the project explained to them in a manner appropriate to that child or young person's communication needs. The advocate will observe behaviours to indicate their acceptance of my presence where the child or young person is not able to give overt consent and/or is not able to understand to give valid informed consent.

I would also like to talk to at least one staff member who knows the child or young person well and can comment and reflect on advocacy for that child. However, I would not wish to cause disruption to the routine and would be sensitive to appropriate times for this to take place. Individual consent to participate will be sought from staff, including if they are participants in a meeting the advocate is attending with the child or young person.

All observations and records are kept strictly confidential and anonymised, and the results will be reported in a research paper available to all participants on completion.

If you have any questions about this research, please email me at greenawj@uni.coventry.ac.uk

I confirm this project is approved by Coventry University Ethics (Project Reference Number: P52267).

Yours sincerely,

Jo Greenaway

Jo Greenaway BA(Hons) QTS, MA
greenawj@uni.coventry.ac.uk
Tel: 07419 122640

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Appendix 2 ii Information for Advocates

Children and Families Research
Faculty of Health & Life Sciences
Coventry University
Priority Street
CV1 5FB



Information Sheet for Advocates

PhD Research: to examine advocacy and “non-instructed” advocacy in England for disabled children and young people with complex communication needs.

Thank-you for considering participation in my research into advocacy with children and young people. The following will provide more information for you to decide whether you would consent to participate in the research.

My research will focus on:

- Observing the advocacy relationship
- Observing communication between yourself as advocate and child or young person.
- Understanding the perspectives and reasoning around advocacy and ‘non-instructed advocacy’
- Understanding challenges, barriers and opportunities of ‘non-instructed advocacy’

Why have you been asked to participate?

As an advocate working with children and young people with complex communication needs, your insight and work is invaluable to my research. I want to be able to observe the advocacy process and interactions to keep the child or young person at the centre of my research, rather than just interview people around them. This means I would like to observe your practice, but please be reassured that this will not be about judging your practice at all.

Do I have to take part?

No. The project will be agreed with your advocacy agency, but you as an individual can agree or not agree to take part. Your individual consent will be sought. At anytime, you can ask to withdraw from the research project. You can also ask for observations and data collected regarding yourself to not be used in the writing up of the research (up to 21 days after study ends).

Jo Greenaway BA(Hons) QTS, MA
greenawj@uni.coventry.ac.uk
Tel: 07419 122640

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What do I have to do?

Nothing apart from continue to work as you normally do. I wish to observe advocacy in action, so if possible ignore me!

At anytime you can ask me to leave if you feel the child or young person is uncomfortable with my presence. I do not want to disturb the advocacy relationship.

Sometimes I may ask questions, but this will not be during your interactions with the children or young people you are working with. I will be writing and reflecting on what we talk about, but no details will be recorded that could identify you, or your clients. I may ask to see records, but this will only be after your agency gives permission and any other relevant persons and this will only be to see how different people see the same situation; it will not be a reflection on your work.

I may ask to do a recorded interview part way through and at the end of my research. This will help to confirm my observations. Again, you may decide you do not wish to be recorded, and this will be respected.

What are the risks and benefits of taking part?

I am aware that you will be working to develop and maintain a relationship with the child or young person and there is the risk that my presence may affect this. I want to reduce this risk as far as possible, and so will just be observing and not trying to establish a relationship myself with the child or young person.

The benefits could include having the opportunity to reflect on advocacy practice and discuss the challenges and benefits of advocacy. Any information will be anonymised and I will not be judging or reporting on your practice (except in the case of Child Protection/Safeguarding concerns as I am duty bound by the Local Authority and University Ethics Guidelines).

Data protection & confidentiality

All documentation and recordings will be coded and anonymised. These will be stored securely according to the regulations of Coventry University ethics and Data Protection Law.

No setting, advocate, child or any other participant would be identified

Ethical Approval has been granted by Coventry University Ethics Board Project Reference Number: P52267



What if things go wrong? Who to complain to

I will be observing with permission of your agency and the settings in which you are working. If you are concerned or wish to make a complaint, please contact your agency and

Professor Olivier Sparagano
Coventry University
Priory Street
Coventry
CV1 5FB
ethics.hls@coventry.ac.uk

What will happen with the results of the study?

I propose to share findings of the study after completion of my PhD and provide written information on the findings to all participants who are interested, including you as an advocate.

The research will be published, but individuals will not be able to be identified.

Further information/Key contact details

Please do not hesitate to ask any questions about this research before consenting to take part. I will be happy to meet with you to discuss further.

My e-mail address is : greenawj@uni.coventry.ac.uk

Telephone 074191 122640

Appendix 2 iii Information for Parents/carers

Children and Families Research
Faculty of Health & Life Sciences
Coventry University
Priority Street
CV1 5FB



Information Sheet for Parents and Carers or Responsible Persons

Project: to examine advocacy and “non-instructed” advocacy in England for disabled children and young people with complex communication needs.

Thank-you for considering your child’s/ ward’s participation in my research into advocacy and ‘non-instructed’ advocacy with children and young people. The following will provide more information for you to decide whether you would consent for your child/ward to participate in the research. You may also be asked whether you would consider participating in the research yourself.

As you may know, advocacy is a way in which people can have a voice in decisions made about their lives. I have worked with children and young people within education and social care and know that there is not much research about advocacy, especially for disabled children and young people with complex communication needs. This is why I want to observe and understand more about advocacy to influence future policy and practice.

My research will focus on:

- Observing the advocacy relationship
- Observing communication between your child and their advocate.
- Understanding the perspectives and reasoning around advocacy and ‘non-instructed advocacy’
- Understanding challenges, barriers and opportunities of ‘non-instructed advocacy’

Why has your child been asked to participate?

Your child has been asked to participate as they are receiving advocacy support and their school/residential placement is in agreement to my observing the advocacy interactions.

Does my son/daughter/ward have to take part?

Jo Greenaway BA(Hons) QTS, MA
greenawj@uni.coventry.ac.uk
Tel: 07419 122640

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No. You as a parent/carer/responsible representative can agree or not agree to take part on behalf of your child. At anytime, you can ask to withdraw your child from the research project.

You can also ask for observations and data collected regarding your child to not be used in the writing up of the research (up to 3 weeks after the end of the study).

What will my child have to do?

I want to be able to observe the advocacy process and interactions to keep your child or young person at the centre of my research, rather than just interview people around them. Your child will not be asked to do anything. They will be observed during their advocacy session. I want to just watch and listen only, so as not to disrupt the advocacy relationship.

Please feel free to contact me with any questions about your child's participation in this research.

What will I have to do?

For a few children or young people in my research I would like to chat to parents/guardians about their perspective on advocacy and how it is/has/has not supported their child. This will be recorded in a semi-structured interview. If you would like to be considered, please contact me. Your consent will be sought separately to consent on behalf of your child/ward.

What are the risks and benefits of taking part?

So as not to affect the advocacy relationship, I will not be seeking to question your child, but just to observe. Hopefully this will not be disruptive to the advocate nor you child.

I hope that the results of my study will be able to influence advocacy practice and policy in future, particularly for other disabled children and young people with complex communication needs.

Data protection & confidentiality

All documentation and recordings made will be anonymised, so I will not be using you or your child's name. Any records will be stored securely according to the regulations of Coventry University ethics and Data Protection Law.

No setting, advocate, child, parent nor any other participant would be identified

What if things go wrong? Who to complain to

If you are concerned or wish to make a complaint, please contact XXXXXX and

Children and Families Research
Faculty of Health & Life Sciences
Coventry University
Priory Street
CV1 5FB



Professor Olivier Sparagano
Coventry University
Priory Street
Coventry CV1 5FB ethics.hls@coventry.ac.uk



What will happen with the results of the study?

I will share information on the findings to all participants who are interested, including yourself as a parent/carer/responsible person after finishing my PhD. As far as possible, the findings will also be shared with the children and young people themselves.

The research may also be published in academic and care journals and reports, but individuals will not be able to be identified. Please let me know if you would like to be informed.

Further information/Key contact details

Ethical approval: - This research has been approved by Coventry University Ethics Committee
Project Reference Number: P52267

Please do not hesitate to ask any questions about this research before consenting to take part. I will be happy to meet with you to discuss further.

My e-mail address is : greenawj@uni.coventry.ac.uk

Telephone 074191 122640

Appendix 2 iv Consent form (advocates and parents)

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Priory Street
CV1 5FB



Informed Individual Consent

Project: to examine advocacy and “non-instructed” advocacy in England for disabled children and young people with complex communication needs.

Please tick

1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving a reason.

☐

3. I understand that all the information I provide will be treated in confidence.

☐

4. I understand that I also have the right to change my mind about participating in the study for a short period after the study has concluded (3 weeks).

☐

5. I agree to be observed and audio recorded as part of the research project and understand conversations will be anonymised to protect my identity.

☐

6. I agree to take part in the research project

☐

Name of Signatory and Position

Signature of participant:

Date:

Jo Greenaway BA(Hons) QTS, MA
greenawj@uni.coventry.ac.uk
Tel: 07419 122640

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Appendix 2 v Parental consent on behalf of their child

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Faculty of Health & Life Sciences
Coventry University
Priory Street
CV1 5FB



Consent on Behalf of Child or Young Person

PhD Research: to examine advocacy and “non-instructed” advocacy in England for disabled children and young people with complex communication needs.

**Please
sign/initial**

1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions.

2. I understand that the participation of is voluntary and that I am free to withdraw consent on their behalf at anytime without giving a reason.

3. I understand the Researcher and Advocate will endeavour to obtain agreement for’s.... participation, and at anytime may conclude that my son/daughter/ward does not wish to proceed with the research project.

4. I understand that I have the right to change my mind about participating in the study for a short period (3 weeks) after the study has concluded

5. I understand that all the information I provide and any observations made by the researcher will be treated in confidence (subject to Child Protection/Safeguarding Guidelines).

6. I agree for to be observed as part of the research project and for their records to be accessed.

7. I agree for to take part in the research project

Jo Greenaway BA(Hons) QTS, MA
greenawj@uni.coventry.ac.uk
Tel: 07419 122640

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Appendix 2 vi Letter for parent responses

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Faculty of Health & Life Sciences
Coventry University
Priory Street
CV1 5FB



Dear Parent / Carer,

Thank-you for your consent to observe your child during the visits of the advocate from XXXXXX . I have now carried out my observations and would like to also have the views of some parents regarding advocacy with their child.

If you would like to contribute, please complete the enclosed form and send it back to me using the self-addressed envelope provided. If you would prefer to have an informal chat, please email me at greenawj@uni.coventry.ac.uk to arrange a convenient time for me to call.

All responses will be anonymised, and records will be stored securely according to the regulations of Coventry University ethics and Data Protection Law.

Kind regards,

Jo Greenaway

Jo Greenaway BA(Hons) QTS, MA
greenawj@uni.coventry.ac.uk
Tel: 07419 122640

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Appendix 2 vii Parental feedback form

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Questions for parents/ Carers

How did you find out about the advocacy service?

How do you feel about advocacy?

What has advocacy meant for your child?

Any other comments regarding advocacy provision or practice.

Many thanks for your participation.

Jo Greenaway BA(Hons) QTS, MA
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Tel: 07419 122640

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Appendix 3i Observational Framework

Observational protocol JMG



CYP Code	AC	Setting Code	OB no.
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Environment-
Context – historical / sequence of visit
Intention – of specific interaction
Players involved

Sequence of events/interactions
Advocacy elements- Rights? Choice? Information? Decisions?
Behaviours- reactions
Distractions/ observed issues?
Reciprocation of communication

Approach –methods of Advocacy?- overt/covert?
Advocate Feedback re. observed situation- Pre
Advocate Feedback re. observed situation- Post
Other players feedback?

Researcher's response to what is observed:

Future questions/follow-up?

Appendix 3ii Non-Verbal Detailed Observation Pro-Forma

[illegible]

Appendix 4 Interviews

Information for advocates for interviews

Children and Families Research
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Information Sheet for Advocates (Interviews)

PhD Research: to examine advocacy and “non-instructed” advocacy in England for children and young people with complex communication needs.

Why have you been asked to participate?

I am researching advocacy with children and young people with complex needs, including ‘non-instructed’ advocacy. I would like to conduct interviews with advocates around their experiences working with disabled young people up to the age of 25. If you have had advocacy experience with disabled children or young adults, I am particularly keen to find out about your experiences and your views as your insight and work is invaluable to my research.

Do I have to take part?

No. The project has been agreed with your agency but you as an individual can agree or not agree to take part. Your individual consent will be sought. At anytime, you can ask to withdraw from the research project (up to 21 days after you have been interviewed).

What do I need to do?

Please fill out the short form attached, giving information as to how you would like me to contact you and whether you would prefer a telephone interview or face-to-face interview.

I will then contact you prior to our recorded conversation to answer any questions and to confirm you are willing to be recorded.

When I interview you, I will ask some questions about your work as an advocate, including your thoughts on non-instructed advocacy. I will also ask you to look at case studies. If at any time you do not wish to answer questions, this will be respected.

Please be assured that all information will be anonymised and any cases you use to illustrate your experience will not be identifiable. This is why I am also using case studies.

What are the risks and benefits of taking part?

The benefits could include having the opportunity to reflect on advocacy practice and discuss the challenges and opportunities of advocacy. You as an advocate will not be identified and I will not be judging or reporting on your individual practice (except in the case of Child Protection/Safeguarding concerns as I am duty bound by the Local Authority and University Ethics Guidelines).



Data protection & confidentiality

All documentation and recordings will be coded and anonymised. These will be stored securely according to the regulations of Coventry University ethics and Data Protection Law. No setting, advocate, parent, child or young adult or other persons would be identified.

We will process your personal and/or sensitive personal data in accordance with the Data Protection Act 1998 ("the Act") and General Data Protection Regulation 2016 ("GDPR"), and keep it confidential. We will dispose of your data securely in accordance with the Act and GDPR, we will securely destroy your data after five years. The Data Protection Act 1998 ("the Act") gives you the right to access information held about you. Your right of access can be exercised in accordance with the Act. Any access request will be subject to a statutory fee of £10 to meet our costs in providing you with details of the information we hold about you. Questions, comments or requests about your personal data can be sent to enquiry.ipu@coventry.ac.uk

Ethical Approval has been granted by Coventry University Ethics Board Project Reference Number: P52267

What if things go wrong?

If you are concerned or wish to make a complaint, please contact your agency and

Professor Olivier Sparagano
Associate Pro Vice Chancellor
Coventry University
Priory Street
Coventry
CV1 5FB
Olivier.Sparagano@coventry.ac.uk

What will happen with the results of the study?

I propose to share findings of the study after completion of my PhD and provide written information on the findings to all participants who are interested, including you as an advocate. It is anticipated that the research will be also be published in both academic and practitioner journals.

Further information/Key contact details

My e-mail address is : greenawi@uni.coventry.ac.uk

Telephone 074191 122640

Many thanks,

Jo Greenaway

APPENDIX 5 – Vignettes used in fieldwork

Appendix 5 i. DYLAN

Part 1

Dylan is a 10-year-old boy who has been referred to your service by his parents. They wish him to have an advocate in order to access further psychological/ Child and Adolescent Mental Health Services [CAMHS] support with his self-biting and increasing aggressive behaviours. They report he has been assessed previously, and was given support within school. They are concerned that the advice given to school is not being carried out and school are not helping as much as they can. Dylan has an Education Health and Care [EHC] Plan review in 4 weeks time. They describe Dylan as having Severe Learning Disabilities and Autism.

Part 2

You visit the parents. Dad appears very anxious and mum is very keen for you as the advocate to make sure he “gets the support he clearly needs “(her words). You agree to arrange to see Dylan at school.

When you arrive at school, the teacher and teaching assistant appear to be open and accepting of your role as an advocate.

You observe Dylan. He does not speak, but sits and looks up when the staff sing with the pupils and responds to the use of PECs. He is included in activities.

You witness an episode of self-biting and aggression as the pupils are encouraged to clear the tables. Staff ignore his vocalisations then give him an object with instructions (PECs and verbal) to place it in the red tub. Dylan ceases self-biting and complies.

On talking to the staff afterwards, they explain that they try their best, but their time is divided between the other young people also with Special Needs in his class. They also say mum lets Dylan get away with anything at home and wants a magic wand to cure him rather than sticking to routines that the speech and language therapist suggests.

Appendix 5ii SHABNAM

Part 1

Shabnam is referred into your service by the community nurse. She is concerned that mum is resistant to support and Shabnam has had a Percutaneous endoscopic gastrostomy [PEG] fitted recently and several changes of social worker in the last year which has affected respite / short break provision. The community nurse states mum has agreed to advocacy support for her daughter, but suggests she may change her mind. Shabnam is 16 years old and has a de-generative condition.

Part 2

You arrange to see both mum and Shabnam at home after school. There are several young children in the house and you observe Shabnam looking around towards the children laughing. Shabnam is in her wheelchair in the middle of the room. After the children are collected by a cousin to go to the Madrasa, you explain to mum and to Shabnam what your role is and you understand Shabnam has had several different social workers. Mum then she starts crying. You establish that mum does not speak English as her first language, she appears frightened of the future for her daughter. She is worried that the respite centre does not meet her cultural needs and finds it difficult to cope with the PEG feeding and changes in social worker.

Part 3

You visit Shabnam in her respite placement several weeks later. Shabnam is sat around a table in the dining room with 3 other clients and 2 staff members. You establish eye contact with Shabnam and she responds positively, you talk to her in a low quiet voice and she continues to look at you. A staff member then sits the other side of Shabnam and starts telling you (in a loud voice) that they think Shabnam has an issue with her hormones and periods and mum doesn't really care.

Appendix 5 iii BILLY

Part 1

Billy is nearly 18. Billy has an Education, Health and Care /Transition planning meeting in 2 months time. You have been asked to advocate for Billy as a 'Looked After' young person with limited communication and a Learning Disability.

When you visit Billy, you use communication cards to help explain your role. Billy repeatedly asks about a sister Trish and ignores the communication cards. You ask Billy if it ok to ask the staff about Trish. You find out that Trish is an older sister. Trish is twenty-four years old.

Part 2

You build up a relationship with Billy and establish that Billy meets Trish once a month with staff support.

At the Education, Health and Care [EHC] meeting, more information is revealed. Billy has been in care for the last 4 years due to domestic violence within the family- some 'perpetrated by Billy' on the mother. Trish has been asking for access and for Billy to live with her and her boyfriend Jake, instead of at the foster placement.

There are concerns as Trish is pregnant, but the Multi-disciplinary team [MDT] agree to increased access alongside looking at other options for Billy's future.

Part 3

You continue to work with Billy as she establishes a relationship with her sister. One afternoon, Billy seems distant and appears uncomfortable. When you mention Jake, she stands up and throws the chair across the room.

Appendix 6 Questions for Semi-structured interviews

N.B.

Part 1 was sent at least 24 hours prior to interview

Questions asked to all in bold type

Bullet points are prompts

Consent and understanding

Confirm read information

Reiterate data protection – anytime stop interview/delete- assurance
anonymity

Confirm consent and process

Demographic information

Age

Ethnic background

Languages

Experience outside of advocacy

Experience in advocacy

Training in advocacy

Training specific to non-instructed advocacy

DYLAN

Part 1

What are your thoughts and how might you approach this?

Policy /Legislation?

What would you find out before?

Part 2

What are your immediate thoughts and how might you approach this?

Communication Tools?

Parents

Professionals and carers different opinions- common in NIA experience?

Common scenario?

SHABNAM

Part 1

What are your thoughts and how might you approach this?

Legislation? Age?

Parents

Referrals from health professionals?

Part 2

What are your immediate thoughts and how might you approach this?

Communication with Shabnam?

Main issues for Shabnam?

Come across language and resistance?

Common difficulties in language?

Communication between parents and other professionals?

Issues with families?

Part 3

What are your immediate thoughts and how might you approach this?

Common scenario?

MDT working?

BILLY

Part 1

What are your thoughts and how might you approach this?

Legislations/policies?

Common scenario.

Looked after children/ disabled-

Pathway/ Transition planning team in local authority?

Part 2

What are your immediate thoughts and how might you approach this?

Prompts

Legislation?

DV?

Other professionals?

Family rights?

Part 3

What are your immediate thoughts and how might you approach this?

Legislation/Policies

Gender?

Safeguarding
Peer/ managerial support

Explain end of vignettes- anything you might want to add?

Understanding of non-instructed advocacy

Next part is general about advocacy and non-instructed advocacy.

How would you define NIA?

Boundaries?

Watching Brief- any other?

Professionals awareness of non-instructed advocacy?

What do you see as the challenges and opportunities of advocacy?

Thanks and confirm consent.

Appendix 7 Table of Literature review documents (Chapter 4)

[Type text]

Author	Title	Year	Country	Grey/ Peer
Brady, L	Where is my advocate? A scoping report on advocacy services for children and young people in England	July 2011	England	REPORT Office of the Children's Commissioner
Care Quality Commission (CQC)	Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism; Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability or autism	2019		Interim report CQC
Dalrymple, Jane	Constructions of advocacy: an analysis of professional advocacy in work with children and young people	2003		THESIS
Department for Children, Education, Lifelong Learning and Skills (DCELLS, Wales), Elsley, S,	<i>Delivering advocacy services for children and young people 0–25 in Wales.</i>	2011	Wales	Gov dept
Fazil, Q., Wallace, L. M., Singh, G., Ali, Z., and Bywaters, P.	'Advocacy makes you feel brave' : advocacy support for children and young people in Scotland.	2010	Scotland	REPORT Scottish Government
Fields, Karen	'Empowerment and Advocacy: Reflections on Action Research with Bangladeshi and Pakistani Families Who have Children with Severe Disabilities'	2003	England	Peer Reviewed Journal Article
Franklin & Knight	Advocacy for children with learning difficulties and communication support needs - the use of peer advocates and the effect of the role of the advocate	2009		THESIS
Griesbach, D & Waterton, J,	Someone on our side: Advocacy for disabled children and young people	2011		REPORT The Children's Society
Knight, A. and Oliver, C.	Improving advocacy for children and young people: principles and minimum standards.	2012	Scotland	REPORT Scottish Government
Longfield., A	'Advocacy for Disabled Children and Young People: Benefits and Dilemmas'. <i>Advocacy for Children: Children and young people's advocacy in England</i>	2007 June 2019	Peer Review England	Peer Review REPORT Office of the Children's Commissioner

[Type text]

Longfield., A	<i>Implementation of the UN Convention on the Rights of Persons with Disabilities: Submission to inform the CRPD List of issues on the UK</i>	2017	England	REPORT Office of the Children's Commissioner
Longfield., A	Helping children get the care experience they need: Independent advocacy for children and young people in care	2016	England	REPORT Office of the Children's Commissioner
MacCarthy	Disability Advocacy Project: A review of the work of the All Decisions Project 2006 – 2008	2009		Childrens Society
McGrath	Choices and Voices: Advocacy and Participation for Disabled Children and Young People	2010		Mencap
Mitchell, F	When will we be heard? Advocacy provision for disabled children and young people in England	2007	England	Report Childrens Society
Morgan	Childrens views on advocacy	2008	England	OFSTED Children's Rights Director England
National Assembly for Wales	Further review of developments in the provision of advocacy services to children and young people in Wales.	2010	Wales	Gov Dept
National Youth Advocacy Service (NYAS)	Independent Advocacy in Child Protection Guidance for Policy Makers	2013	England & Wales	Advocacy Charity
National Working Group on Safeguarding Disabled Children	Safeguarding Disabled Children in England How Local Safeguarding Children Boards are delivering against Ofsted requirements to protect disabled children: findings from a national survey	2016	England	Joint with OFSTED
Northern Ireland Commissioner for Children and Young People [NICCY]	'Who speaks for us?' review of advocacy arrangements for disabled children and young people with complex needs	2008	Northern Ireland	
Oliver, C. and Dalrymple, J. (eds.)	Developing advocacy for children and young people: current issues in research, policy and practice.	2008	UK	BOOK
Pinney, A.	Understanding the Needs of Disabled Children with Complex Needs or Life-Limiting Conditions	2017	UK	Council for Disabled Children

[Type text]

				and the True Colours Trust
Pona & Hounsell	The value of independent advocacy for looked after children and young people	2012		Childrens Society
Priestley, A	Do looked after children with communication impairments need an advocacy service?	2001		
Scottish Independent Advocacy Alliance (SIAA)	Working with Children and Young People: Guidelines for Advocates	2016	Scotland	Independent advocacy organisation/ network
Scottish Government	Improving advocacy for children and young people: principles and minimum standards: discussion paper.	2011	Scotland	
Thomas, N., Street, C., Ridley, J., Crowley, A., Moxon, D., Joshi, P. & Edwards, A	Independent Advocacy: Impact and Outcomes for Children and Young People	2016	England	Report for CC
Towley, G	<i>Missing Voices</i> Wales Children's Commissioner's Office	2014	Wales	CCO Wales
Townsley, R., Marriott, A., and Ward, L.	Access to independent advocacy: an evidence review	2009		Report for the Office for Disability Issues.gov
Walters, A. (Medway safeguarding Child Board)	Serious Case Review 'Learning for organisations arising from incidents at Medway Secure Training Centre'	2019		Serious Case Review
Wood & Selwyn	The Characteristics of Young People Using Independent Advocacy Services	2013	England	Report

Watching Brief -What is it?

Skills & abilities: developing and using your skills to be as independent as possible

Community presence using, being involved with and contributing to the local community

Continuity having a past, present and future with key people and events in your life

Choice & influence influencing and making choices about your own life

Individuality being a unique and distinctive person in your own right

Status & respect being held in esteem and valued for who you are

Partnerships & relationships having meaningful contact with other people

Well-being feeling physically and psychologically well

The Watching Brief was developed by Asist Advocacy

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Thank-you.